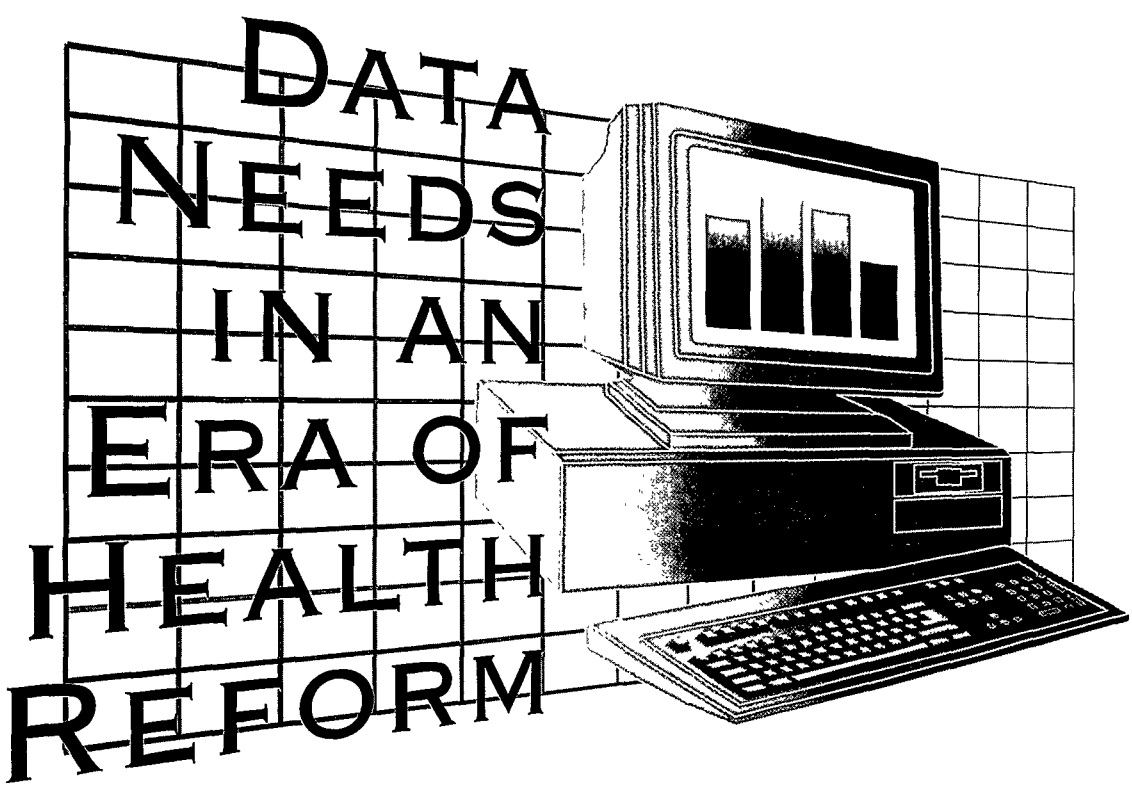


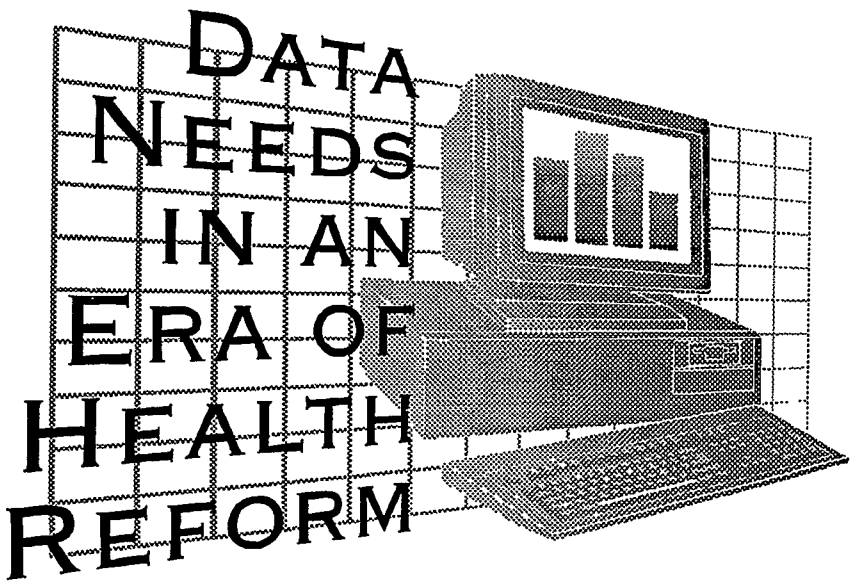
Proceedings

25th Public Health Conference on Records and Statistics and the National Committee on Vital and Health Statistics 45th Anniversary Symposium

July 17-19, 1995
Mayflower Hotel ◆ Washington, D.C.

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics

CENTERS FOR DISEASE CONTROL AND PREVENTION



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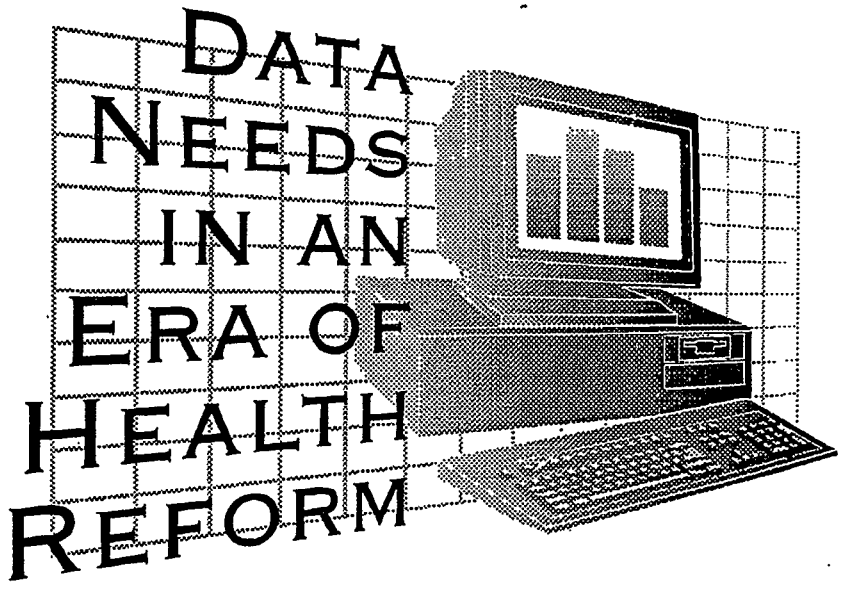
Each Article Has Been Prepared by the Author



25th NATIONAL MEETING
OF THE
PUBLIC HEALTH CONFERENCE ON RECORDS AND STATISTICS

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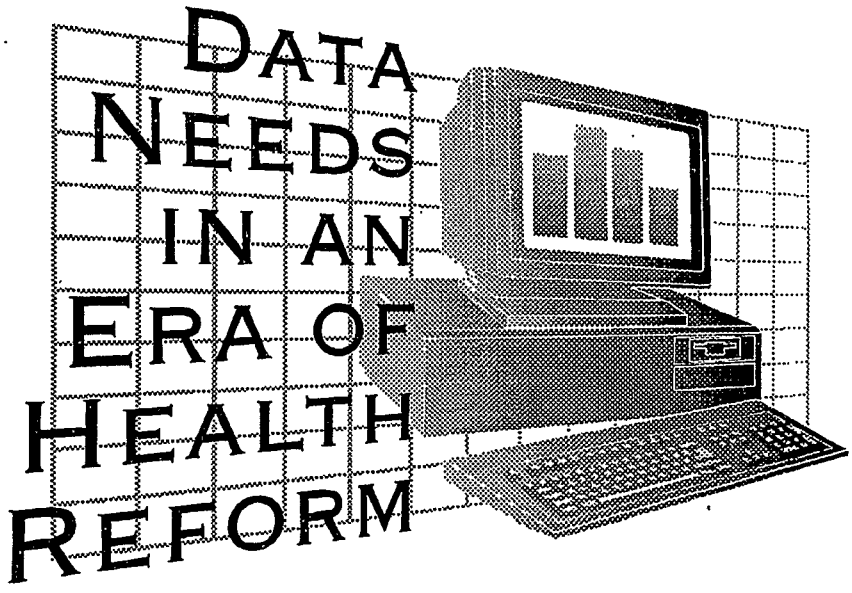

THE QUINTESSENTIAL ROLE OF INFORMATION IN PUBLIC HEALTH

Keynote Address

Roz Diane Lasker, M.D.
Deputy Assistant Secretary for Health (Policy Development)
U.S. Department of Health and Human Services

It is a pleasure and a privilege to be with you this morning, not only to highlight the quintessential role of information in public health, but also to recognize the important roles that many of the participants of this meeting are playing in collecting and using health-related data, and to share with you activities at the federal level that have the potential to reorient data policy in support of population health.

As all of you are aware, this is an incredibly challenging time for those of us who are involved with and care about health information. Information to support the public's health has never before been so important. Yet many forces, including ever tightening budget constraints, are making it increasingly difficult to successfully make the case for investing in data collection and analysis. Partnerships between federal, state, and local governments, and between the public and private sectors are becoming increasingly necessary to meet community-wide information needs. Yet it is difficult to promote the cooperation required to support these partnerships in an environment in which health information is viewed more as a competitive weapon than as a tool for the public good.

This morning, I would like to highlight specific areas where the varied participants of this conference can work together to enhance the usefulness of health information. By the end of my talk, I hope that many of you will be encouraged to join in these activities. More important, however, I hope that many of you will become actively involved in the data policy debate. Ultimately, the availability of information to support population health depends as much on policy as on technology and methodology. So far, policy relating to health data has been debated primarily by those representing the business side of health care (purchasers and large providers/payers) and by advocacy groups. Adding to the table professionals who actively collect and analyze data for broad-based public health purposes can bring an important perspective to bear when decisions are being made. The extent to which each of you keeps abreast of developments and weighs in where and when it matters will be an important factor determining how policymakers view health information and how that information is collected and used.

THE GROWING IMPORTANCE OF HEALTH INFORMATION

As the health system and the role of government undergo rapid changes, the need for useful information is becoming increasingly important. We need information to:

- track the impact of the dramatic changes that are occurring;
- measure health system performance (this is particularly important as we move toward a smaller and less regulatory role for government); and
- provide the knowledge base that we need to take effective action and improve performance (for example: Where are interventions needed? Which interventions are most cost-effective? What is the outcome when various interventions are implemented?)

For those involved in the health care system, information is needed about the quality, availability, and costs of care, and to support consumer/purchaser choice and health plan report cards. For those of us involved in public health and health policy, the perspective and need for information is even broader. The bottom-line question here is "How do we get the biggest bang for the buck in health"? And although most of our country's attention and investment focuses on the health care system, the answer to this question does not lie in the medical sector.

As most of you know, more than 70 percent of premature deaths in this country are due to personal risk behaviors and environmental hazards that the medical system can do little about. To make an impact on health and reduce disparities in health status, we need the capability to provide population-based services that reduce or eliminate threats to health in the community. To do this, we need information that goes beyond medical care, encompassing the entire population (including those who do not seek out care), the environment, and the population-based public health system.

RETHINKING HEALTH DATA STRATEGY IN A CHANGING ENVIRONMENT

For the last two and a half years, I have been working with many others in the Administration to improve the capacity of information systems at federal, state, and local levels to meet these needs, and to see how we can

harness emerging electronic data networks to support population health. A key point that has emerged from this work is that, as our need for health information grows, we, at the federal level, need to rethink our data collection strategy.

Simply put, current approaches are not meeting needs. Externally, our partners in states and communities are urging us to reduce their reporting burdens, which do not necessarily provide them with useful information. Internally, it is becoming increasingly apparent that our currently fragmented, poorly coordinated, and episodic data collection efforts have resulted in unnecessary duplication, critical data gaps (both nationally and at state and local levels), competition over roles, and inefficient deployment of scarce information resources.

Fixing the problem isn't easy, however, because the environment in which we are collecting health-related information is changing rapidly. On the one hand, the health system itself is a moving target, both in the way personal health care services are delivered and the way community-wide public health needs are being met. Dramatic changes are taking place in the organization of each of these sectors of the health system, and in the way they interact (i.e., their respective roles, responsibilities, relationships, and funding streams). Currently, we do not even have a typology that adequately characterizes the health system -- much less one that still will be meaningful five or ten years from now.

Another complicating factor is that advances in telecommunications and high performance computing are changing the way people communicate with one another and the way that information is recorded, collected, used. Because of the efforts of many in this room, considerable headway has been made in the planning (and now early implementation) of logically integrated health information systems. These systems take many different forms, but one feature they have in common is that they allow information collected routinely in the course of delivering medical care or public health services to be aggregated and used for multiple health-related purposes.

Integrated information systems have the potential to overcome much of the duplication and fragmentation that characterizes current data collection efforts. Yet we are limited in realizing the full potential of these systems because, currently, we do not have a national framework for health information. Such a framework would include:

- uniform data standards that meet the needs of the different types of people who record and use health information;
- a uniform system of unique identifiers (not just for individuals, but also for other units of interest, such as providers, worksites, restaurants, wells, and employers);
- secure environments for linking data and creating anonymous files;
- uniform privacy provisions that protect individuals while permitting critical analytic uses of health data; and
- appropriate data sharing policies that provide communities with the complete data they require to meet health needs.

A third element in the changing environment is the growing movement toward benchmarking and performance measurement. Activities at various levels -- including Healthy People 2000, health plan report cards (such as HEDIS), assessment protocols for public health agencies, state efforts in benchmarking, Performance Partnership Grants, and the measurement of federal program performance through GPRA and the National Performance Review -- are providing a substrate for clarifying goals and documenting the extent to which public and private investments make a difference in population health. Good information is essential to the success of these initiatives. In particular, we need to develop a data infrastructure that supports accurate, reliable, and comparable measures of results that can be achieved.

Unfortunately, however, we are living in an environment of growing fiscal constraints. Consequently, in spite of all of the talk about benchmarking and the need to document value for dollars spent, budget pressures and the movement to downsize government are making it increasingly difficult to obtain adequate funding or personnel for the data activities that support these measurements. As many of you are aware, appropriators are used to thinking about data as an administrative cost rather than as an integral part of carrying out and evaluating health programs. In fact, both federal and state legislators often oppose funding for information systems because they perceive it as drawing funds away from the delivery of health services. This point of view is especially ironic in public health, where data collection and analysis undergirds the successful delivery of services. In a constrained environment, attention to information becomes even more important as a means of targeting scarce dollars toward services that can accomplish the most in terms of health.

A final contextual point to consider relates to partnerships. For various

reasons, the current environment demands collaborative relationships between the federal government, the states, and the private sector in data-related activities. A broad range of expertise is needed to put health information systems into place. Data to protect and improve health come from diverse sources within the community. Qualified users span many different professions. And the costs of information systems require a broad base of financing.

Nonetheless, several factors make it difficult to move forward in this regard. On the one hand, there is a lack of consensus about the appropriate role of the federal government vis-a-vis the states, and of government vis-a-vis the private sector. Moreover, many states and communities lack both the policy framework and the structural mechanisms to bring potential partners in health-oriented information systems together. Without clarity about roles, adequate incentives to collaborate, or a forum for social interaction, feasible data strategies to support population health may not get started or may falter before implementation.

APPROACH AND ACTIVITIES OF THE PHS DATA POLICY COMMITTEE

A year and a half ago, the Assistant Secretary for Health established a Public Health Service (PHS)-wide body -- the Public Health Data Policy Coordinating Committee -- to highlight the quintessential role of information in public health and to develop, coordinate, and implement data policies in support of population health. That committee has highlighted the importance of adopting a broad systems approach to health information in the future, involving:

- data from integrated health information systems as well as surveys;
- a balanced approach to data collection, including information about: (1) health and functional status, (2) behavioral, environmental, occupational, and infectious risks to health, (3) the capacity and functioning of the medical and public health systems; and (4) the costs, utilization, and financing of individual and population-based health services;
- the capacity to link different types of data together and to aggregate them geographically so that it is possible to look at important interrelationships (for example, between health status and medical care; personal risk behaviors and sociodemographics; environmental hazards and health care costs; and the emergence of managed care and funding for essential public health services);
- comparable health-related information at national, state, and local levels;
- meaningful and reliable data to support program measurement and performance measurement; and
- federal/state and public/private partnerships to develop data strategies and to collect information.

In its mission to improve data in support of population health, the Committee has focused on seven policy areas: the National Information Infrastructure (NII); health data standards; privacy; integrated information systems; performance measurement; survey strategy; and health statistics. Its activities and progress in these areas, which I will outline in the remainder of my talk, are the product of a close working relationship with a broad range of players involved in health and information: public health professionals at state and local levels; other relevant components of the federal government; clinicians; researchers; experts in informatics, high performance computing, and telecommunications; and states and communities that have been moving forward with integrated information systems.

The NII and Population-Based Public Health

The purpose of the National Information Infrastructure Initiative is to enhance the basic infrastructure for telecommunications and computer technology in all sectors of the U.S. economy. From the start, health has been identified as one of the key sectors that can benefit from NII technology. But so far, NII grants related to health have primarily supported applications of high performance computing and telemedicine to the delivery of medical care to individuals. Relatively little attention has been paid, by either the private or the public sector, to applications that could improve the capacity of communities to carry out the nonclinical or population-based functions of public health (i.e., services that identify local health problems, prevent epidemics and the spread of disease, protect against environmental hazards, and assure the quality and accessibility of health services).

Last April, the PHS sponsored a conference at the National Library of Medicine, during which leaders in the NII and population health communities had an opportunity to come together, to explain their work to each other, to delineate the barriers that currently discourage application of NII technologies to the information problems of population-based public health, and

to lay out a comprehensive strategy for moving forward. At this conference, five barriers emerged, above and beyond basic resource constraints and the limited appreciation by both the public and policymakers of the importance of population-based public health. These include:

- lack of nationally uniform policies to protect privacy while permitting critical analytic uses of health data;
- a lack of nationally uniform, multi-purpose data standards that meet the needs of the diverse groups who record and use health information;
- insufficient awareness of the applicability of NII technologies in meeting the information needs of population-based public health;
- a public health workforce that lacks essential information technology skills; and
- organizational and financing issues that make it difficult to integrate information systems or bring potential partners together.

Those attending a strategy session following the conference proposed a strategic plan that capitalizes on what a broad range of actors -- state and local public health agencies, federal agencies, professional associations, educational institutions, and other groups -- can do individually and together to overcome these barriers. A copy of the white paper was included in your conference materials. If you would like to learn more about this project or get involved in the strategic plan, please contact Betsy Humphreys at the National Library of Medicine or any of the other people listed at the end of the white paper.

Health Data Standards

Both the PHS and the Department of Health and Human Services have begun work on federal aspects of the white paper strategic plan. Following a mandate from the Vice President, the Department is establishing a Department-wide Data Council to develop and coordinate policy in the areas of data standards, privacy, and data collection. The Council will interact with other Departments and Agencies in the Administration, and with an external advisory committee representing the views of the broad range of stakeholders. A key focus of the PHS Data Policy Committee in this regard has been to emphasize the need for the Department to work closely with the full range of parties in the public and private sectors who collect and use health-related information and to support uses of information that promote population health as well as cost containment and medical care.

In the area of health data standards, there is a growing awareness in both PHS and the broader Department that the key to this issue is not simply reaching <u>any</u> agreement (for example, by locking stakeholders in a room until they pick one of many coding systems to use). The real challenge is to identify and implement standards that meet the needs of the diverse groups that use health information. Without multipurpose standards, data recorded in electronic information systems may not be accurate. If information is entered in these systems in a nomenclature that is neither meaningful to nor actively used by the people who are recording it, those people are unlikely to have much interest in whether the information they record is accurate or not. And if information that is recorded for one purpose cannot also be used for other purposes, we are not going to achieve the administrative simplification that so many are talking about.

In the current environment, which some have likened to a "Tower of Babel," it is very hard to move forward with integrated information systems. States attempting to do so must develop their own standards, negotiating with major health care payers and providers as well as other parties whose data are critical to meeting health information needs. These efforts are not only time-consuming, they risk the adoption of standards that are more suitable for one purpose, such as paying claims, than for meeting the needs of clinicians, researchers, and the public health community. When standards differ over geographic boundaries and data systems, it is impossible to aggregate information.

Technically, there may be a solution to the standards problem in the near future. The Unified Medical Language System (UMLS), which is being developed under the auspices of the National Library of Medicine, is a vocabulary that was originally developed to retrieve medical information from the literature. Currently, it is also being used as the basis for computerized medical records. With over a quarter million concepts currently defined, it will soon be possible to record data in integrated information systems in the same detailed and meaningful form in which they are entered in computerized patient records (i.e., a form that works for clinicians when they take care of patients).

The real potential of the UMLS, however, stems from the fact that information recorded in this vocabulary can be mapped to any of a broad range of coding and classification systems, all of which are contained in the UMLS metathesaurus. That means that information can be recorded in an unbiased form, useful for patient care

at the point it is being delivered, and then can be translated automatically into coding systems appropriate for other purposes, such as CPT for billing or ICD for morbidity or mortality reporting.

Until recently, the UMLS has focused primarily on medical treatment. Currently, however, the National Library of Medicine is working to expand the UMLS to unique public health concepts, making it a true health vocabulary that can accept information from machine readable public health records as well as clinical records. In addition, the National Library of Medicine is beginning to fund demonstrations to test the UMLS in clinical and public health settings as well as in integrated health information systems. Systems designed with the flexibility to accept information in this form will be able to capitalize on the increasing use of the UMLS by clinicians and public health professionals in their computerized records.

Privacy of Health Information

The PHS Data Policy Committee has addressed the issue of privacy from the framework of population health. In this context, protecting the privacy of individually-identifiable information is critical since inappropriate use of health information can harm people and be a health hazard in itself. But supporting the usefulness of health data is equally important since, without information, it is simply not possible to improve health. Consequently, the challenge is to find ways to protect the privacy of individuals while permitting critical analytic uses of data.

Although this is a difficult task, it may not be impossible to achieve, especially if we keep in mind that many uses of data to support population health do not require the user to identify any particular individual. Identifiers are required in order to link data and create useful analytic files. Thereafter, files can be stripped of identifiable information and still be of benefit for many (although certainly not all) health-related purposes. Viewed from this perspective, policies to support privacy and the usefulness of health information need to incorporate both protections for individually-identifiable health information and secure environments to link identifiable data and to create anonymous, public use files.

Currently, without these types of policies in place, some state and federal regulations protect privacy by preventing the linkage of data from different systems, seriously hampering the identification of health problems or the ability to take effective action. In states without sufficient or clear privacy protections, providers and consumers may be reluctant to provide identifiable information for statewide databases. These barriers impede our ability to address interstate health problems, which affect half of all Americans who live near a state border.

Interestingly, quite a bit of progress in this area was made in the Congress last year in the context of health care reform. Both Representative Condit and Senator Leahy incorporated comprehensive privacy provisions in information systems bills. These bills, which had bipartisan support in both houses of the Congress, balanced privacy and access to data by incorporating not only provisions to protect the privacy of individually-identifiable health information (in all forms), but also secure environments for linking data and creating anonymous files.

If passed, these bills would have established a national framework for protecting privacy while assuring access to health information to promote the public good. But it is important to keep in mind that these bills were prepared in the context of health care reform -- a reform in which there were rules of the game requiring health plans to provide information and preventing them from using health information for such nefarious purposes as redlining and cherrypicking. In the current unregulated environment, a pro-data and pro-privacy strategy is far more difficult to achieve because even public use files have the potential to harm people.

Currently, many groups are involved in efforts to educate policymakers about the chilling effect of the lack of privacy legislation on the development of integrated health information systems. The Departmental Data Council is planning to begin its activities in this area by working on the development of model laws, and by identifying best practices for protecting the privacy of health information and for ensuring security in electronic data systems.

Integrated Health Information Systems

An area in which the PHS Data Policy Committee has been particularly active involves support for the development of integrated health information systems at the state level. Numerous projects are currently underway. Some will facilitate electronic claims processing and coverage verification in the health care system. Others are designed to integrate the delivery of health care to individuals across numerous state and local agencies. In broader public health-oriented systems, clients encompass not only people, but also restaurants, hospitals, waste systems, swimming pools, and wells, and the Internet is used to link public health agencies to each other and to academic health centers.

Although these developmental efforts are somewhat different in approach, they raise common policy, implementation, and political issues with which many in the public and private sector are grappling. At the present time, however, project developers have little opportunity to benefit from the knowledge or experiences of others. States and the federal government have not established a mechanism for assessing the impact of proposed changes in their information systems on each other. Moreover, the categorical nature of many health programs impedes the development of integrated information systems, both through categorical information systems that speak different languages (in terms of vocabulary, software, and data standards) and through prohibitions on the use of categorical funds for developing or maintaining information systems that benefit programs in addition to the one for which the funds were appropriated.

The PHS Data Policy Committee has held several meetings with leading edge states to identify common concerns and to develop a productive course of action. Future meetings will bring together representatives from states and relevant federal agencies to discuss such issues as the UMLS, privacy, and the impact of proposed changes in Departmental data systems on state integrated information systems.

Another project just getting underway is the construction of a registry of state developments in integrated health information systems. This registry is intended to serve as more than a compendium of projects. It is envisioned as a dynamic database of current information that will be updated regularly by system developers and that can be accessed and searched easily by a broad audience of users. To achieve this goal, the content, format, and indexing of the database for electronic searching will be developed in close collaboration with those who will be providing information to the system as well as those who will be using it. Various mechanisms will be tested for dissemination, including a World Wide Web Server.

Through the newly proposed Performance Partnership Grants (PPGs), which I will discuss in more detail later in this conference, the Committee put forward policies that, if enacted, will substantially reduce the number of categorical information systems while giving states the flexibility to use PHS grant funds to develop and maintain integrated information systems that benefit multiple programs. Importantly, the new grants would protect current levels of funding for surveillance, and would exclude funds related to data collection and analysis from the state administrative cap.

Public Health Performance Measurement

Nothing highlights the importance of data more than performance measurement, and the PHS Data Policy Committee has been working through two mechanisms to advance the data infrastructure for performance measurement in public health: Performance Partnership Grants and an Institute of Medicine (IOM) panel on the use of performance measurement to improve community health.

Performance Partnership Grants establish a new basis for grant relationships between the federal government and the states, in which the two will work together as partners to achieve measurable health objectives. Considerable groundwork in this area has already been set through the Healthy People 2000 process, through benchmarking efforts in a number of states, and through federal activities such as GPRA and the National Performance Review. An internal feasibility study conducted by the PHS earlier this provided convincing evidence that, although data collection efforts can clearly be improved, meaningful public health results can be measured now through existing federal-state data systems.

This fall, the Department of Health and Human Services will initiate a partnership process to identify and measure objectives for the PPGs. The process will consist of a series of regional meetings to obtain structured input from a broad range of stakeholders -- states; local governments; tribal governments; public health professionals; other public, private, and professional groups; interested citizens; and federal officials -- about the results they want to achieve, and believe it is feasible to achieve, through these programs.

Working from information generated through the regional meetings, an independent technical panel with comprehensive knowledge of national and state data systems will identify which of these results can be measured now as objectives, and recommend how federal-state data systems could be improved to measure other important PPG results in the future. The panel's report will be used by the Department to prepare a provisional menu of objectives for each PPG, which will be distributed widely for review and comment before it is finalized. As changes in federal and state data systems are implemented in the future, the menu of PPG objectives will be periodically refined to more closely reflect the results that states, the federal government, and interest groups want to achieve.

While the regional meetings and technical panel are designed to support implementation of PPGs, their importance extends far beyond this particular legislative initiative. The goal of the

process is to lay a strong foundation for a continuing federal-state partnership in data collection and benchmarking. This should enhance our ability to document how federal and state investments make a difference in public health, regardless of the way federal grant programs are structured.

After states or communities identify the improvements in health outcomes they would like to achieve, they still need to identify the range of actors that can make an impact on these results, clarify the specific roles various actors can play, monitor the extent to which these actions make a difference, and promote a collaborative environment in which providers of personal health care services, essential public health services, and other groups can work constructively together toward common goals. The IOM Committee on Using Performance Monitoring to Improve Community Health has been charged with looking at the potential usefulness of a comprehensive system of public health performance monitoring in addressing these issues, in effect, by thinking about such a system as a community-wide health management tool. In its report, the IOM Committee will illustrate such a process by identifying sets of indicators that can measure the performance of a broad range of actors in addressing specific health problems, and by generating a "tool-box" that can help others develop sets of indicators for their high priority health problems.

Survey Strategy

Many of you are aware of the Department's plans to rethink its data collection strategy, in particular, its newly proposed survey integration plan, in which the National Health Interview Survey would function as a sampling "nucleus" for many population surveys, and as the hub for a series of longitudinal panels, including one providing better information on medical insurance and expenditures. As these efforts move forward, the PHS Data Policy Committee has emphasized the need to have broad and structured input into the decisionmaking process so that the Department's data collection strategy is rationalized through a framework that supports population health. If all stakeholders have a voice at the table, we will be in a better position to ensure that strategies to expand one type of data (for example, expenditures) do not come at the expense of critical information related to health status and risks to health. Equally important, we will begin building a constituency that can better educate appropriators about the importance of data collection activities in improving population health.

With respect to specific projects, the PHS Data Policy Committee incorporated a $4 million initiative in the President's 1996 budget request to obtain comprehensive data on the capacity and functioning of the public health infrastructure (i.e., the full range of federal, state and local government agencies responsible for the health of the population). Proposals are currently being solicited to develop a strategy for collecting these data. The contractor will work through an intergovernmental partnership, building on data currently being collected and on work that has already been accomplished in developing consensus definitions for essential public health services, evaluating public health performance, and obtaining information on public health expenditures. The project is intended to bring into a cohesive framework many disparate data collection efforts. By doing so, it will provide policymakers at many levels with information to assess the impact of rapid changes in the health care system on the public health infrastructure, and will serve as a comprehensive basis for health services research in public health.

Other components of the President's 1996 budget request would address data gaps and improve analytic capacity in various ways: by expanding available information on disabled persons and health providers (including substance abuse and mental health providers), by improving the National Health Accounts, by strengthening the Area Resource File, and by enhancing the linkage of information related to population characteristics, health problems, and health resources at the community level. As part of its survey rationalization process, the Department is planning to work on several other fronts as well: facilitating federal/state partnerships in health surveys, consolidating provider surveys, improving the usefulness of its capacity surveys by developing a workable typology to characterize the evolving health system, and integrating its health surveillance and grant reporting systems.

Health Statistics

As part of the Administration's reinventing government initiative, the Department has given priority to strengthening its capabilities in health statistics. Moving in this direction is important not only to improve the availability of information for setting the nation's health agenda, but also to undergird health policy decisions with sound, credible data. Since health statistics are, in effect, a "public utility" covering a broad range of issues -- including health status, risks to health, the delivery of individual and community-wide health services, the capacity of the health care and public health systems, and health expenditures

-- the benefits of strengthening this function extend far beyond the Department to other agencies in the federal government, to policymakers and health professionals at state and local levels, to the private sector, to advocacy groups, and to various segments of the research community.

As options are being considered, the PHS Data Policy Committee has highlighted a number of points. The essence of statistics, turning raw numbers into useful information, requires a comprehensive view of health data and a close working relationship with a broad range of users. At the same time, however, it is critical that the statistics function remains outside of the political or policy fray -- in other words, that its operations and analyses remain impartial and unbiased. A strong statistics agency, therefore, needs to be viewed as independent, and avoid the appearance or reality of being captured by any given user or point of view.

As recent events make clear, there is also a need for a statistics agency that can function as a "center of gravity" around which a vision for useful, coordinated data systems can be formed. Such an agency could institutionalize the progress that has been made thus far in integrating general purpose health surveys, bringing some but not all of these surveys under one roof. It could facilitate the establishment of information partnerships with states and the private sector, coordinating health surveys conducted at multiple levels, and creating opportunities for greater use of data from administrative and programmatic systems. It could function as a methodologic resource center, providing the Department and others with a critical mass of expertise to support statistical analyses and to develop the indicators that undergird performance measurement. In addition, it could serve as a steady voice for a broad-based, balanced program of data collection committed to meeting the needs of a wide range of data users.

Consideration of these issues within the Department comes at an opportune time, as the search process has started for a new Director for the National Center for Health Statistics, as major changes are being made in the Department's data policy function and data collection strategy, and as the Congress considers steps to more closely coordinate or combine federal statistics agencies. It also comes at a critical time. Unless we are successful in identifying what really needs to be measured and in forming partnerships to collect this information, the nation will not be able to afford to meet its health data needs. And unless we can demonstrate to policymakers and the general public the usefulness and practical value of health data to them, appropriators will be unlikely to provide the federal government or the states with adequate data funding. According to a story I heard recently, which I hope is not apocryphal, the head of health statistics in a nearby country regularly attends Cabinet meetings, providing information on-line and in user-friendly graphic displays for federal policymakers. I can't think of a better way to highlight the quintessential role of information in population health.

Various organizational and functional options for a statistics agency are now being considered, both in the Department and the Congress. In this matter, and for many other data issues that I covered in my talk, now is the time for those actively involved in health data collection and analysis to keep abreast of developments and to bring their perspectives to bear in the policymaking process. Broad, balanced, and active input is the sine qua non of informed decisionmaking, especially in times of rapid change. Your input has been important thus far and will be even more important in the future. We, in the Public Health Service and the Department of Health and Human Services, look forward to working with you on these vital issues.

EMERGING ISSUES IN PUBLIC HEALTH; CONSEQUENCES FOR DATA NEEDS

Jan A.J. Stolwijk, Yale University

The ability to assess the health of the public in a society or any political subdivision of a society is a function of the quality and detail of the data that is available. Demographic data in the form of births, deaths and age distribution in the population constitute a minimum that may not even be available in some societies lacking the infrastructure to gather such data. In countries such as the former Soviet Union where such data were available, the measurable derivatives such as life expectancy at birth or at any age, and more specifically the infant mortality rate, showed a deterioration of the state of the health of the public that preceded the breakdown of that particular political and economic system.

Within the United States the National Center for Health Statistics since its inception in 1962. has been charged with the surveillance of the health of the U.S. public. In a nation that is concerned with the right to privacy of its citizens to a much higher degree than many other nations at a similar level of economic development NCHS has provided us with a continuing record of measures of the health of the U.S. public that are the envy of other nations.

The efforts of the National Center for Health Statistics for the U.S. have provided us with an exemplary record of tracking the state of the health of the nation over a nearly forty year period with a degree of sensitivity and specificity that can inspire pride of achievement while at the same time providing us with a keen awareness of challenges that are not being met. International comparisons of life expectancy and infant mortality in countries that are at a high level of economic development generally show that there is a price to pay for the amount of heterogeneity in education, socialization, employment opportunity and income that a society is experiencing. As a result, comparisons between Sweden or Switzerland on the one hand, with limited diversity, and the United States, with considerable diversity, tend to rate the health of the public better in Sweden and Switzerland than in the U.S.

In public health the twin objectives of the maintenance of health and the prevention of disease are primary. NCHS maintains a continuing historical record of the health of the public measured in a variety of ways, especially tracking agreed upon national objectives such as the Health Objectives for 1990 and for the Year 2000. There will likely always be a tension between the objective of preventing disease and premature death and the objective of curing disease and postponing death. This tension manifests itself in terms of resource allocation and organization of health services. A good example is collecting data on childhood immunization which clearly should have a high priority, but its benefits are delayed, its costs are immediate, and tracking is not simple. In addition there are difficulties in the way the public health systems and the curative health care systems are organized.

Loss of access to medical care and the rate of rise in the cost of medical care have become important national concerns and unless suitably addressed are likely to express themselves as eventual reductions in the state of health of our population.

Decision makers in the public as well as in the private sector are facing complex questions, and ongoing and anticipated transitions in the health care system. In the last year I have been receiving an unusual number of requests by Health Maintenance Organizations and insurance companies to provide them with the names of recent doctoral graduates who could help them start programs in the area of outcome research. Judging by the beginning salaries they are offering, they are placing a high priority on these new efforts.

The Federal Government is also in the process of increasing the amount of information collected in various surveys that would help in the description and analysis of different forms of organization of health care in terms of access, cost, acceptance and outcome. Part of the motivation for this process is driven by the wish to "reinvent government", and another motivation is to increase the amount of data collection and analysis relevant to health care policy.

As a frequent user of data collected by various Government agencies and as one who has collected population based data for special studies on a number of occasions, I am somewhat concerned when important surveys such as the Health Interview Survey are being redesigned in their basic structure in order to accomodate current health care policy needs.

Existing surveys with a long and successful history have arrived at the current form and format as the result of continuing reviews and negotiation with a number of stake holder organizations within and outside the Government. Many advocacy groups have to rely on the results of such surveys to monitor the comparative state of health of their constituencies as well as any trends that develop over time. Reductions in the coverage might threaten the continuity over time of such surveillance.

Population based surveys and the instruments on which they rely are the product of numerous compromises in conflicting factors such as:

- the amount of information obtained
- the burden on the respondent
- the response rate
- the quality of the information obtained
- the cost of the survey

We can assume that existing surveys have been optimized with regard to such factors as listed above. The advent of new technology in interviewing such as Computer Assisted Personal Interviews and Computer Assisted Telephone Interviews brings about perturbations in currently optimized surveys.

When a large number of surveys are in the field it is always useful to consider whether there are overlaps in data collected, whether a particular sample could serve more than one survey, or whether development costs could be reduced by consolidation. Tempting as such proposals for consolidation are, it is extremely important to scrutinize the savings claimed for such consolidation efforts. Each survey is already the result of an optimization of a number of conflicting demands of the type listed above. Consolidation of one or more surveys will likely result in a new optimization in which one or more of the existing surveys will be diminished in favor of new objectives.

As an example one or more of the following is likely to occur:

- if costs are to be lowered then the product of sample size and the amount of data collected for all surveys under consideration will be likely to be reduced
- if two or more surveys are merged, the

individual respondent burden can not be increased without reducing participation rate; it is therefore likely that each consolidated survey will have to give up a substantial fraction of its content

- although additional joint distributions will be recorded, others will be lost, and the result will be a shift of resources into the new joint distributions, and a loss of continuity for the lost distributions

It would seem important to always have in view that data should be collected at the source that is heavily involved in the generation of these data. Medical care costs associated with rare events should be gathered from the institutions which provide such care, and population based survey frames are a poor source for such data. It is obviously important to get the joint distribution of income levels and income sources, and of sources of medical care. Perhaps it would be more efficient to add questions about the type and source of medical care to an already existing survey with a long history such as the Current Population Survey or the Survey of Income and Program Participation. During a time of rapid transitions in the organization of medical care this could provide better tracking of the transition than could be obtained from adding detailed income questions to the HIS Core. In general, there is utility in coordination with survey activities of Departments other than Health and Human Services.

Surveys are designed to have samples that represent populations. It may become increasingly important to have samples designed with subsets valid for States since a number of functions and responsibilities for preventive care and medical care organization are or will be centered in the States. If differences in approach to the organization of preventive and medical care arise between States it would be possible and important to monitor differences in outcome.

If the Health Interview Survey and its sample can be made a launching platform for more specialized studies, and longitudinal panels, there will be obvious advantages in that there will be linking at the respondent level. A possible problem will be that the burden on individual respondents will inevitably increase, with some likelihood of increased dropout rates, but the advantage of obtaining joint distributions of additional variables is an important benefit.

Many European countries, and especially the Nordic countries have in place a central registration system which constitutes a very rich database at the personal level addressable through a unique lifetime personal identifier. A large number of studies have been made possible by linking these data sources collected for a variety of purposes, including vital statistics, civil registries of residence, collection of taxes, employment records, disease registries, medical care records, etc. Such registries contain the whole universe of the population and obviously can be used to answer questions for which we have to mount special or continuing surveys. It is clear that such a universal registration system cannot be implemented in the United States for a large number of reasons. However, it would seem that we could make more use of linking individual records collected for different reasons by different institutions. Especially in the area of health care organization and health care costs as measured in claims or payments very large databases exist which are the property of State and Federal Agencies, and similar databases exist in the private sector in Health Maintenance Organizations, insurance companies and in associations of hospitals at the State level.

It might be useful to explore how we could facilitate and promote the construction of linked records that are stripped of all identifiers after having been linked on the basis of an identifier such as the Social Security Number or a State Identification Number and one or more variables. Such studies can now be done, and are being done, but usually there are substantial barriers to overcome. Many policy questions that come up are difficult to address with statistical surveys, lend themselves much more to studies based on already existing data that have to be linked at the record level.

In 1987 the Public Health Committee of the Connecticut Legislature formally asked the Connecticut Academy of Science and Engineering to evaluate the Economic Impact of AIDS Health Care in Connecticut. The Connecticut State Health Department maintains a registry of persons diagnosed with AIDS as a part of the National Registry, and the then Department of Income Maintenance was the repository for Medicaid claims and payments. The two files were linked within the State Computer Center on a State Identifier and a subset of all Medicaid claims and payments on behalf of persons with AIDS was produced for analysis. The State Health Department produced a file of persons diagnosed with AIDS that was stripped of all identifying information other than the State Identifier. These two files allowed for a comprehensive analysis of Medicaid supported cost of medical care of persons with AIDS in Connecticut. It was found that 49% of adult Persons with AIDS had their medical care reimbursed by Medicaid, as did 85% of pediatric patients. This percentage was slowly increasing during the 1980's. The average Medicaid payment per year for those served by Medicaid was $34,420 with 75% of that in the form of hospital inpatient charges, 19% for hospital outpatient and medical payments and 5% for drugs. This was an example of providing a fairly prompt (1 year) answer to policy-relevant questions at low cost from already collected data through record linking. Without the ability to produce a linked file it would have been very difficult to provide the estimate requested. It was not possible to deduce the AIDS status from the Medicaid records, and without linking with the AIDS register no reliable estimates could be made.

In another example of cooperative research that involved access to a State Registry for Birth Defects in New York State we wished to determine whether proximity of the mother's residence to a hazardous waste site was a risk factor for birth defects. The mother's residential adddress in the birth certificate was linked to the TIGER files developed by and for the U.S. Census in order to develop latitudes and longitudes for that residence which could be related to the latitudes and longitudes that could be derived from the Registry of Hazardous Waste Sites for New York State maintained by the Department of Environmental Conservation. The resulting file did contain all the information from the Birth Defects Registry including the geographic coordinates, and all the information from the Registry of Hazardous Waste Sites including the characteristics of the site and its geographic coordinates. As a result we could determine the association of different birth defects with distance from a hazardous waste site, and with the characteristics of the site. The use of pre-existing information, combined with a facilitation of the record linking in a manner that protected the privacy of all concerned made it possible to conduct a study of great statistical power which detected a small but

significant association.

If the above indicates a prejudice about the value of being able to link different data sources, I confess. In the discussions that I am aware of that are concerned with improving the efficiency of data gathering, and the need to gather more data for research in support of policy evaluation and development, there is almost no discussion of the possibility of merging existing databases. If we would like to tap the potential for this type of linkage which I believe to be substantial it will be necessary to prepare for such linkages by pursuing the following, not necessarily in the order presented here:

- in surveys or data sets that are to be linked there needs to be a key on which such links can be made. In the U.S. the Social Security Number suggests itself, although there may be some problems with that
- HHS may find it useful to produce and make available in one document codebooks of all surveys or data sets that contain data that might be relevant to health care policy or public health preventive potentials
- there needs to be agreement on a protocol that provides effective assurance that no individual whose data are already recorded in one of the files being linked will be able to be identified in the linked file or at any time in the process
- there may need to be an agreement about the computer facility that will carry out a linkage and produce the linked file, especially if files from different agencies or institutions need to be linked

The announced intent to integrate, consolidate or merge different HHS surveys by using the HIS as a sampling frame to mount a number of more specialized surveys, while taking advantage of the NHIS Core data is in principle a sound way of using linking of surveys, in this case linking through selection of participants for other surveys from the HIS Core, based on characteristics recorded in that core.

Without intending to be critical of what was clearly an effort under extreme time constraints and strong directives it is worth mentioning the claimed benefits and liabilities that were perceived by the participants in the process. The benefits claimed were:

- coordination of efforts
- filling in of gaps in coverage
- potential of linked surveys
- reduced respondent burden
- improved efficiency in all parts of the survey process
- improved ability to focus on high-priority, data needs

Among the liabilities that were considered in the Survey Integration Plan:

- Time pressure in implementation
- Larger overall budget: vulnerable for reductions
- Interrelatedness increases vulnerability to breakdowns of any one element
- It may be more difficult to accomodate demands for special analyses

It would appear that the benefits are items that are objectives to be pursued without any guarantee of being achieved, whereas the liabilities are likely to stare us in the face from the start. This observer would urge that the product of the task force working on the integration of HHS Surveys be the starting point of a negotiation and implementation phase that would include input from constituencies and other Departments and Agencies at the Federal and State levels. I am sure that all of us look forward to an improved data gathering effort that maintains the strengths already established and at the same time anticipates policy research needs at the Federal and State level and recognizes the benefits of more linking of data bases at the record level.

DISCOVERING, DESCRIBING, AND UNDERSTANDING SPATIAL-TEMPORAL PATTERNS OF DISEASE USING DYNAMIC GRAPHICS

William F. Eddy, Carnegie Mellon University*
Audris Mockus†

1 Introduction

We describe a set of exploratory tools to investigate and to model spatial-temporal patterns of diseases. The essential idea is to integrate statistical and visual modelling with interactive visual representation. The disease data represents multiple spatial-temporal processes where each reported observation (number of cases in space-time region) is an aggregate quantity (averaged over the particular region). The implemented visual representations of such data include static and dynamic maps and time series plots. The modelling tools include transformations, color mappings, smoothing, aggregation, estimation of dependence structure, and other models. The toolset can be easily extended by a non-expert using the S language (Becker, Chambers, and Wilks, 1988). We start by describing the data, then describe our approach and some features of the implementation.

2 Data

The data we use were obtained from the Centers for Disease Control and Prevention (CDC) which operates the National Notifiable Diseases Surveillance System (NNDSS)

Name	# of Cases	# of Missing	Name	# of Cases	# of Missing
Asep-Mening	135327	399	GC-Mil	31221	2529
Brucellosis	1053	13469	Syphilis-(Total)	457212	341
Chickenpox	374072	36404	Syphilis-Civ	350404	3901
Diphtheria	30	16755	Syphilis-Mil	566	25303
Enceph-Prim	15346	266	Rabies-Animal	79813	220
Post-Enceph-(Total)	2666	229	Antrax	4	21747
Post-Enceph-CPox	1350	21746	Botulism	372	21747
Post-Enceph-Mump	25	21747	Cong-Rubella	68	21747
Post-Enceph-Other	468	21747	Leprosy	2745	5263
Hep-B	280586	464	Leptospirosis	388	21746
Hep-A	328964	467	Polio-Total	17	21747
Hep-unsp	66036	480	Polio-Paralytic	16	21747
Malaria	15353	290	Polio-Nonparalytic	0	21747
Measles	69714	406	Polio-Unspecified	1	21747
Mening-Inf (Total)	36703	242	Plague	65	21747
Mening-Inf-Civ	7576	25293	Psittacosis	535	21747
Mening-Inf-Mil	10	25305	Rabies-Human	19	21747
Mumps	64535	1045	Cholera	164	21747
Pertussis	38241	403	Hep-NA-NB	40045	5942
Rubella	13980	410	Legionellosis	11379	5924
Tetanus	411	16710	Measles-Indigenous	48668	8660
Tuberculosis	327441	351	Measles-Imported	3500	8664
Tularemia	2816	226	Toxic-Shock-Syndrome	3424	8664
Typhoid-Fever	5786	293	BOT-Food	132	21747
RMSF	11067	294	BOT-Infant	198	21747
Typhus-Murine	20	38782	BOT-Other	42	21747
Trichinosis	166	21747	H.-Influenzae	10718	30233
Gonorrhea-(Total)	10522000	338	Lyme-Disease	26525	30763
GC-Civ	8874720	3901			

Table 1: The list of diseases and numbers of cases

in partnership with the Council of State and Territorial Epidemiologists (CSTE). The CDC collects weekly provisional information on the occurrence of diseases that are defined as "notifiable" by CSTE. Further details concerning the NNDSS can be found, for example, in Chorba et al. (1989).

The dataset contains weekly by state reports on 57 diseases for the period between 1980 and 1994. There are 783 report weeks in this period and the reports are provided for 51 states, 3 territories and New York City. The names of the reported diseases, the total number of cases over the reported period, and the number of missing reports are in Table 1. The table conveys a general idea of how widespread each particular disease is and how much care is taken to report the disease cases.

3 Multivariate Interactive Animation System For Map Analysis

We previously analyzed similar data on the disease mumps in Eddy and Mockus (1993). The analysis we performed produced successively smoother non-interactive dynamic maps of the incidence rates and a dynamic map of the residuals from a two way analysis of variance model. Here we generalize this approach to multiple diseases. We have designed a system to integrate dynamic and static maps, transformations, smoothing, and other techniques for spatio-temporal modelling and visualization. We refer to this system as MIASMA (for Multivariate Interactive Animation System For Map Analysis).

The system accepts observations in the form of a three dimensional array. The first dimension ranges over all regions in space (e.g., counties or states). The second dimension ranges over all time periods (e.g., days, weeks, months, years). The third dimension lists all the quantities of interest (e.g., population size, number of cases for a particular disease, incidence rates for a particular disease, or derived quantities). Notice, that we only consider quantities that are averages over regions in space and time. The first two dimensions of the array define a dynamic map and the last one implies that there may be multiple dynamic maps.

The input to the system can be either original reported data or the output from a statistical model (e.g. residuals and/or effects of a spatial temporal model). Those, we can successively fit models and inspect residuals until we obtain a satisfactory fit.

The system is implemented as a selection of different classes of tools. The most important classes include multiple visual representation, transformation, handling of missing values, aggregation and smoothing, superpositions of several quantities, and statistical model fitting toolsets.

We separate modelling tools into two groups: models for visual representation, and models for statistical analysis. The models for visual representation must be tightly integrated into the system to allow adequate interactive response, while statistical models can be loosely integrated via file sharing. We separate the implementation of modelling and visualization tools to simplify extensions to the system.

3.1 Display

An example display of our system is given in Figure 1.

The system consists of the main control window and various view windows. The control window contains menus and selection lists. Modelling and transformation methods are controlled from the main window. In Figure 1 the data on

the disease *aseptic meningitis* is selected and the rank transformation is being used. The main window also contains the current date (year and week) for the dynamic map view shown at the bottom. A time series plot of the disease incidence in Alabama is in the window overlapping the control window. The state and the disease can be selected interactively using scrollbars at the bottom and at the left of the time series plot.

3.2 Visual Models

The models/tools for visual representation include view selection, spatial smoothing, time interpolation, transformation, color mapping, display of missing values, and display of multiple quantities. The available views are time series,

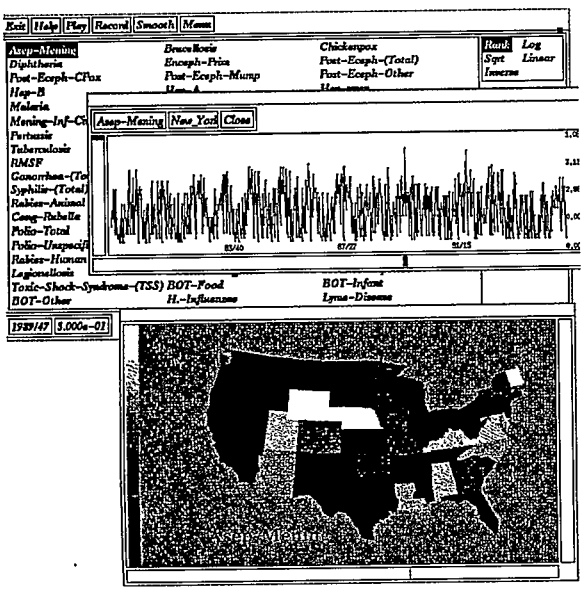

Figure 1: Control window and two views of the MIASMA

static maps, and dynamic maps. Each type of view is presented in a separate window and an unlimited number of windows can be created for each view.

The time series view presents the time series of the data for a particular quantity and spatial region over the available time period. Two scrollbars allow selection of the spatial region and quantity of interest.

The static map view displays a static map of the data where color of a pixel in the window encodes the value of the quantity at the particular location in time and space. Since the quantities are aggregates over a space-time region we provide several interpolation techniques. The simplest one just shows a constant value within each region. As with a time series view the two scrollbars allow selection of the quantity to be displayed and the time moment.

The dynamic map view is an animation of a static map. As with the static map, several interpolation techniques are provided. The simplest—piecewise constant interpolation—shows a constant value within each region and within each time interval. A slightly smoother animation can be obtained by interpolating linearly between two time intervals, namely, two maps are computed for each time period as the key frames and then linearly interpolated for the intermediate frames. The number of intermediate frames can be changed to increase or decrease the speed of the animation. A spatially smooth animation can be obtained by spatial interpolation as described in Eddy and Mockus (1993). The smoothing parameter and starting location for the animation can be selected using scrollbars.

We consider spatial and temporal smoothing as a visual model since it facilitates perception of the dynamic map. Time smoothing removes jumps in time (the jumps create a distracting blinking appearance) and smoothing in space hides region boundary artifacts (which are clearly perceived by an observer but are often irrelevant to the quantity of interest). Time-space smoothing represents a simple visual model that allows qualitative (without excessive detail) display of data that was aggregated over regions in time and space. We have found that in a dynamic display it is important to limit the amount of information since it is not trivial to perceive every detail even with the high bandwidth of a human visual system. Smoothing can be viewed as fitting of a statistical model; we discuss that approach later.

Essential visual representation models are various transformations of the data into the range of available display attributes. The simplest—linear transformation—can often be inadequate due to the discrete nature and limited range of display attributes, such as, pixels, colors, patterns. We have found that different transformations emphasize different features present in the data, e.g., few large outliers can make a dynamic map look almost constant if a linear transformation is used. Rank transformation, on the other hand, ignores the outliers and make the distribution of the display attributes uniform over the available range. In addition to linear and rank transformations we have arbitrary power transformations (extended by a logarithmic transformation). In the case of dynamic and static maps we encode the value of a quantity of interest by color. The transformation (mentioned above) converts each value into an integer code in the range between 1 and 256 (code 0 is reserved for the background). Those codes are then displayed according to the colormap that maps each code into a color. The colormap can be selected interactively. For a discussion on how to select colormaps to convey quantitative information see Levkowitz and Herman (1992).

3.2.1 Display of Missing Values

By inspecting Table 1 it becomes apparent that a substantial amount of observations are missing. It is essential to address this problem in constructing a visual representation of the missing data.

We implement a number of ways to address this problem. In the time series view we show the data as small dots. Missing data is absent from the display, although we can infer its presence from the larger horizontal gaps. We take two different approaches in the case of static and dynamic maps. The two alternatives are to leave the missing data

out (use a neutral, background, transparent, or some other color that is not present in the color scale) or to fill in some color using the available data. Currently we show missing values in the background color or impute the color (by taking a median value for each time moment) and add a pattern to indicate that that value was not observed.

3.3 Statistical models

We have found several statistical models very useful to study these data. We start from the simplest but very useful models of aggregation, then consider smoothing methods, a two-way table, estimation of dependence structure, and best linear prediction (kriging).

3.3.1 Aggregation

Various aggregation methods can dramatically reduce the amount of data and simplify the inspection process. By aggregation we mean reduction of the number of observations in our dataset (represented by a 3-dimensional array (diseases, time moments, states)) by combining several cells into a single cell. The aggregations differ in which cells are selected for aggregation (neighborhoods) and in which method is used to produce a single value out of values in the neighborhood. Another operation which we call smoothing operates the same way as aggregation except it does not reduce the number of cells in the data array, i.e., for each cell a neighborhood of cells is defined and then the combine operator is applied to the values in the neighborhood of a cell to produce a single value for that cell. Since the smoothing and aggregation methods are so similar we will consider only aggregation methods. Analogous selection of neighborhoods and combine operators is available for smoothing operations too.

Definition of neighborhoods. We consider several ways to select neighborhoods by selecting a direction in the data array and by selecting the size of the neighborhood. Since the data is represented by a 3-dimensional array $x_{i,j,k}$ the aggregation direction is defined by selecting the index of the array. The first index corresponds to spatial location, the second - to time intervals, and the third - to diseases.

For example, we can aggregate over time intervals with the window size of 4 time intervals to convert weekly data to monthly data. The monthly data array

$$X_{i,J,k} = \mathrm{Agg}(x_{i,4J,k}, x_{i,4J+1,k}, x_{i,4J+2,k}, x_{i,4J+3,k}),$$

where $x_{i,j,k}$ is weekly data array, and Agg() is aggregation operator. The aggregation/smoothing operator can be selected independently of the neighborhood selection. It can range from a simple sum ($\mathrm{Agg}(x,y,z,w) = x+y+z+w$) to an ARIMA filter, where the result represents parameter values of the ARIMA process, or the smoothed version of of the time series.

We can investigate periodic behavior in the dataset by defining appropriate neighborhoods. For example, to produce a standard yearly cycle from weekly data we can aggregate values for a particular week over all years.

Spatial neighborhoods need be treated differently from time neighborhoods. To define spatial neighborhoods we need to define adjacencies between the locations of observations because the simple ordering by time is no longer present. In our case regions A_i (states) form a partition of A (the continental US). We define two spatial regions to be adjacent (or one-adjacent) if they share a common border consisting of more than one point. If there is a region to which they both are adjacent then we call them two-adjacent. Similarly we can define k-adjacent regions. The sizes of the spatial neighborhood is the number k.

It may be of interest to aggregate over different quantities (diseases) in an attempt to capture relationships between different diseases. Any composition of aggregation/smoothing methods can be performed within MIASMA.

Aggregation operators can be divided into several classes: arithmetic, order, selection, composition, and other. The arithmetic operators include sum and variance, the order operators include various quantiles, the selection operators select a value(s) based on position within the neighborhood (section, several sections). Composition of the operators is also possible. More complicated complicated operators are described in the next section.

3.3.2 Other statistical models

Given a complicated structure of observations it seems useful to be able to inspect the model and the residuals. For example, let z_{ijk} be the reported incidence rates of disease k in state i for month j. We can use median polishing to fit a model $z_{ijk} = s_{ik} + t_{jk} + \eta_{ijk}$, where s_{ik}'s are state-disease effects and t_{jk}'s are time-disease effects. Since the model contains a large number of parameters we may inspect the parameters as well as the fit using the tools available in MIASMA. To do that we can use derived datasets $\mathrm{Effects}_{ijk} = s_{ik} + t_{jk}$ or $\mathrm{Residuals}_{ijk} = \eta_{ijk}$ instead of the original observed incidence rates. In particular, the residuals do not have seasonal and longer term trends observed in the disease reports, but can indicate unusually high incidence rates (epidemics).

Another approach is to model the disease as a space-time process. The observed data would represent the integrals of the incidence rate process over the regions A_{ij} in space and time, $x_{ijk} = \int_{A_{ij}} f_k(x)dx$. To predict the process f_k at a particular location in space and time one has to estimate (or know) the covariance function of the process f_k. For a reference on spatial prediction see Cressie (1991). Estimation of the spatial covariance function from aggregate data is described in Mockus (1994).

4 Summary

We designed and implemented a system (MIASMA) to analyze spatio-temporal patterns in a dataset containing weekly reports of 57 diseases in the United States. The system integrates statistical and visual representation tools for interactive modelling and exploratory analysis of similar datasets. The visual representation tools can be used to look at the raw data, at the fitted models, or at the residu-

als from the fitted models. We found that interactive model fitting and exploratory analysis is essential in dealing with large spatial dataset. Our modeling and visualization tools are geared to analyze aggregate data, when observations represent averages over space-time regions of some underlying process. In particular we implement smoothing, interpolation, aggregation, and prediction methods for aggregate space-time dataset. We separated implementation of the visual representation and statistical analysis tools to simplify extensions of our system.

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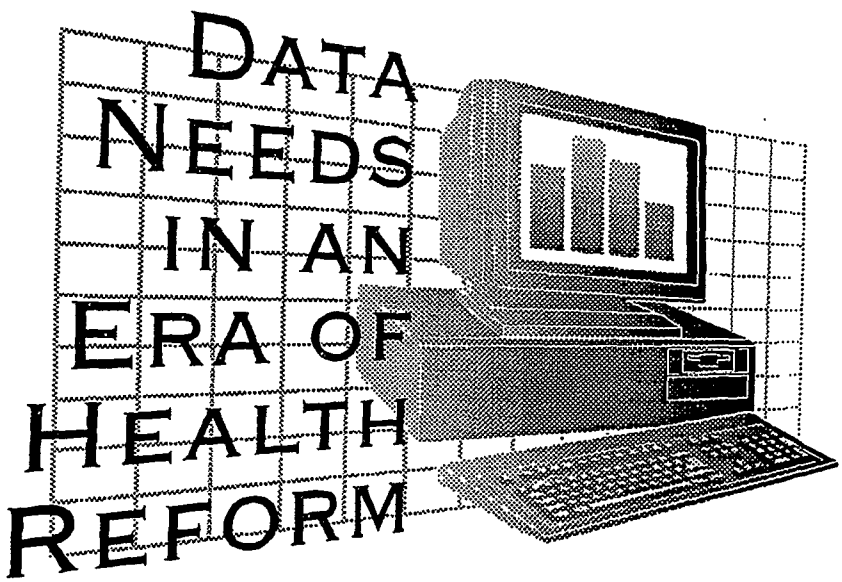
*Professor, Department of Statistics, Carnegie Mellon University, Pittsburgh, PA 15213-3890.

Partially supported by ONR Contract N00014-91-J-1024

†Visiting Assistant Professor, Department of Statistics, Carnegie Mellon University, Pittsburgh, PA 15213-3890.

Session A

Injuries and Violence



STATEWIDE WEAPON INJURY SURVEILLANCE: COMPARISON OF WEAPON INJURY MORBIDITY AND MORTALITY

Victoria V. Ozonoff, Massachusetts Department of Public Health
Catherine Barber, Linda Saltzman, Maxine Schuster

"Violence is a public health problem." That statement and the description of the scope of the problem have become grimly familiar to most of us. In 1992, there were over 37,000 firearm-related deaths in the U.S.--and firearms have become the leading or second leading cause of injury death in at least 15 states. However, firearm-related deaths tell only part of the story; for every firearm-related death, there are many other violence-related injuries. Based on emergency department surveillance, we estimate that there are over 100 other violence-related injuries of any weapon type for every firearm-related death in Massachusetts.

A public health approach to a disease or condition resulting in excess or premature mortality and morbidity encompasses at least three components: surveillance, intervention, and evaluation. Our ability to develop and evaluate violence prevention interventions has been limited by the lack of adequate surveillance data. Due to the limitations of our data systems, we typically have been unable to characterize the nature of nonfatal injuries. The Massachusetts Weapon-Related Injury Surveillance System (WRISS) was developed to address these limitations(1,2).

The surveillance system first was implemented as a pilot program in 1989, with funding from the Centers for Disease Control. That pilot program has been expanded into a statewide surveillance system, with reporting from all 85 hospital emergency departments in the Commonwealth. Today's presentation will summarize the first year of statewide surveillance data and compare these data to mortality data.

System Description and Methods

Since 1927, all Massachusetts physicians have been required to report all gunshot wounds (GSWs) and violence-related sharp instrument wounds (SIWs) to state and local law enforcement authorities. Over 40 other states have similar reporting requirements. Although the Massachusetts statute requires reporting by physicians, WRISS is a voluntary, emergency department-based reporting system in which hospitals also report these injuries to the Massachusetts Department of Public Health (MDPH). WRISS reporting incorporates existing statutory requirements with additional data elements. Based on periodic emergency department record audits, system reporting compliance is estimated to be between 70-80%, and there is no apparent systematic reporting bias. This compliance estimate is significantly higher than the 30% estimated compliance to law enforcement authorities prior to WRISS implementation.

The system has enabled us to describe the number and nature of nonfatal weapon-related injuries, to compare these injuries to fatal injuries, and to describe differences among population groups and geographic areas. In addition, the system's findings are critically important to the development of local violence prevention initiatives. The methodology of the system was developed in a way that would facilitate its replication or modification by other states or localities.

Findings

During calendar year 1994, there were 2865 weapon-related injuries to Massachusetts residents reported to the MDPH: 980 were GSWs and 1885 were violence-related SIWs. By definition, all GSWs and all violence-related SIWs treated in Massachusetts hospital emergency departments are reportable. Excluded are any injuries treated outside of an ED, such as in a physician's office or clinic, and any fatal cases not taken to an ED. Unless otherwise noted, numbers and rates presented here are based on reported cases not adjusted for compliance. Therefore, the actual number of cases and rates are somewhat higher.

Violence-Related Gunshot Wounds: Of the 980 GSWs reported to WRISS, 662 or 68% were violence-related, 17% were unintentional or "accidental," 5% were intentionally self-inflicted, and 11% were of unknown intent. The rate of violence-related GSWs was 11 per 100,000 population compared to 2.7 for unintentional GSWs.

Most victims were male (90%, n=598), although males comprise only 48% of the population. Half of the victims (n=328) were black, nonHispanic compared to 5% of the population. Of the remaining cases, 18% (n=121) were white, nonHispanic and 24% (n=157) were Hispanic. Race was missing or unknown in about 6% (n=41) of cases. GSW victims were young, often very young. Sixty-three percent (n=414) were under the age of 25, with teens and young adults (15-24) accounting for 60% (n=394) of cases. The injury rate for this group was seven times higher than the rate for adults over 24 years old (42.2 vs 5.7 per 100,000). Within the 15-24 age group, teens had a higher injury rate than the 20-24 year olds (47.4 vs 38.1, n=197 for each).

The disposition of ED patients highlights the need for an ED based surveillance system. A quarter (27%, n=179) were treated and discharged from the ED; 57% (n=379) were admitted to the hospital; 9% died in the ED (n=59); the status of 7% (n=45) of victims was missing or unknown. Without an ED reporting system, we would have little, if any, information on the 25-30% of GSW victims treated and discharged. In addition, without E-coding of hospital discharge data, little would be known about the 57% of patients admitted to the hospital. Although E codes have been mandated in Massachusetts beginning in 1994, these data still are unavailable for analysis. In addition, the quality of E-coded data is unknown, and there is a significant time-lag between injury occurrence and data availability.

The development of violence prevention initiatives requires knowledge about the circumstance of the injury, the relationship

between the victim and offender, and the place of injury occurrence. For example, very different prevention strategies might be employed for drive-by shootings in contrast to domestic violence. This information traditionally has been difficult to obtain, and it also has been difficult to obtain as part of ED surveillance. Almost two-thirds (63%, n=354) of violence-related GSW cases did not include victim-offender relationship; data were missing, unknown, or the patient was unwilling to disclose the relationship. In 26% of cases, the offender was reported as a stranger, and in 11% of cases the offender was known to the victim. Reporting for the circumstance of the injury was only slightly better with 54% missing or unknown (n=302). For cases in which circumstance was reported, 29% (n=75) were related to argument/abuse, 39% (n=102) were crime-related, and 32% (n=84) were reported as other circumstances. Fifty-four percent (n=359) of GSWs were reported as occurring on the street, 13% in a house, 14% in other locations. Location was missing or unknown in 19% (n=124) of cases.

Given the large proportion of unknown/missing data, these findings must be interpreted with caution. However, the results are suggestive of areas for further study. It may be that more qualitative, in-depth research is necessary to understand these variables. Surveillance data may be most useful for suggesting areas in which additional research should be conducted.

Unintentional Gunshot Wounds: The development of WRISS was motivated largely by the need to learn more about violence-related injuries. However, because the law requires the reporting of all GSWs, important data on unintentional injuries also have been collected through WRISS. Because most self-inflicted GSWs are fatal and are not treated in the ED, the surveillance system adds relatively little to our understanding of these injuries. Among the 980 reported GSWs, 163 or 17% were unintentional or "accidental." Children and youth under 20 years old were represented disproportionately among unintentional injury cases (50%). Unintentional GSWs tended to be less severe than violence-related ones; only 20% (n=32) of these victims were admitted to the hospital, compared to 57% of violence-related GSW victims.

A partial explanation for the difference in severity was somewhat surprising, namely weapon type. More than half (56%) of the unintentional gun injuries were caused by BB or pellet guns. Forty-seven percent of these injuries were to children under the age of 15. Because these injuries rarely result in hospital admission or death, very little has been known about them. In fact, they often are perceived as minor, and BB or pellet guns frequently are used by children with the knowledge and consent of adults. However, these guns can cause blindness and other eye injuries. Among Massachusetts residents, a quarter of injuries from these guns were to the face or head. Newer, more powerful, BB and pellet guns are capable of even more serious injury--and nationally there are several fatalities each year. Thus, WRISS was able to identify a previously hidden source of gun-related injury for which prevention initiatives can be developed. Although BB gun injuries were more common in small communities, it is interesting to note that in both large and small communities about 23% of BB gun injuries were violence-related. Despite a popular perception that these are toys or sporting guns, they are being used as weapons in interpersonal violence.

Violence-Related Sharp Instrument Wounds: The focus of this presentation has been primarily on violence-related GSWs. However, WRISS is unique in that it also collects information on violence-related SIWs. Information about SIWs is even less available than about GSWs because most analyses of violence-related injuries rely on mortality data, and relatively few SIWs result in death. SIWs are a significant part of intentional injury, and summary data are presented here to supplement the findings on GSWs. Almost three times as many violence-related SIWs (n=1885) as GSWs (n=662) were reported to the MDPH. Until the development of WRISS, only the crudest of estimates of the number of nonfatal SIWs had been available.

Most SIW victims were male (83%, n=1566), although female victims were slightly more common than for GSWs (15% vs 7%). About a third of SIW victims were black, nonHispanic (31%, n=586), about a third were white, nonHispanic (36%, n=687), and 19% (n=355) were Hispanic. Thus, there was considerately more racial/ethnic variation among victims of SIWs than among victims of GSWs, although black and Hispanic victims still were overrepresented. The age distribution of SIW victims was similar to that of GSW victims in that there was a peak in the teen/young adult age groups. However, SIW victims were somewhat older; 42% (n=790) were under the age of 25 compared to 63% of GSW victims. SIWs tended to be less severe than GSWs. Less than a third (30%, n=561) were admitted to the hospital, 55% (n=1041) were treated in the ED and discharged, and 14% (n=265) of cases had a missing or unknown disposition.

SIW victims were injured in a wider variety of places, under more varied circumstances, and were more likely to report being injured by someone they knew than GSW victims. In cases where victim-offender relationship was reported, 57% (n=547) involved persons known to each other, and in 43% (n=408) the offender was unknown to the victim. In 41% (n=656) of cases victim-offender relationship was reported as unknown. Victim-offender relationship was more likely to be reported for SIWs than for GSWs (59% vs 37%). The circumstances of SIWs were different from those reported for GSWs; 44% (n=710) resulted from an argument or abuse, compared to 13% for GSWs; 15% (n=247) were crime-related; and a smaller proportion reported missing/unknown (33%, n=485) than for GSWs (54%).

Advantages of a Statewide System

Statewide surveillance permits analyses of weapon-related injury data in ways that previously were not possible. For example, we now are able to calculate and compare rates on both a statewide and local level. The availability of nonfatal statewide data has enabled us to compare morbidity and mortality data and to calculate case fatality rates.

Demographic differences (by age, race, sex) in violence-related GSW rates already have been mentioned. Rates also varied by size of community. Almost 79% (n=521) of GSW victims lived in large communities (50K+) compared to 37% of the population. Firearm-related injuries were more of a large city problem, primarily because of violence-related injuries. The rate of GSWs in large communities was 30 per 100,000 compared to 6 per 100,000 in small communities--with a rate ratio of large/small of 5. That is, the risk for a GSW was five times higher in a large than in a small community. Rates steadily increased with community size, with Boston, the State's largest city, having a rate of 47 per 100,000. Boston cases accounted for almost half of the total GSW reports. Coupled with the data on age, race, and sex of victims, we can see that young, minority urban males were represented disproportionately among victims of violence-related GSWs.

Through WRISS we also have determined that while violence-related gun injuries tended to cluster in large cities, unintentional injuries were distributed more generally throughout the state. The rate of accidental injuries was similar in large and small communities.

Morbidity and Mortality

A statewide, population-based surveillance system for weapon-related injuries permits the comparison of fatal and nonfatal injuries using both surveillance and vital statistics data. Most analyses of weapon-related injuries have focused on mortality due to the availability of vital statistics or police homicide data and the lack of morbidity data. WRISS has revealed some important differences in the epidemiology of fatal and nonfatal injuries.

For the comparison of mortality and morbidity data, nonfatal cases from WRISS and fatal cases from the MDPH Registry of Vital Records and Statistics were used. WRISS cases that died in the ED were excluded to avoid double-counting. Because the mortality file for 1994 is not yet complete, it should be emphasized that figures presented here are preliminary estimates. For this reason, rates are stated as ranges. The number of nonfatal cases was adjusted for underreporting.

The estimated case fatality rate (CFR) for violence-related GSWs (excluding BB guns) was much higher than for SIWs, 15-17% vs 1-3%. Although women were at lower risk for GSWs, the CFR for females was higher than for males, 30-36% vs 13-15%; the CFR was highest for white females (53-58%) and lowest for black females (19-21%). Thus, although white women had a relatively low risk of GSW injury, they were more likely to die if injured. The higher CFR for white females requires further investigation, for example looking for possible differences in age, circumstance, and victim-offender relationship. CFRs for males and females for SIWs were similar (1-3%).

Youth 15-24 years old accounted for 52% of fatal GSWs and for 62% of nonfatal GSWs. In contrast, this age group represented 16% of fatal SIWs and 40% of nonfatal SIWs. Rate ratios of younger (0-24) to older (25+) victims differed for GSWs and SIWs as well as for fatal and nonfatal cases. For GSWs, the rate ratio was 2.3 for fatal injuries and 3.6 for nonfatal injuries. That is, younger victims were twice as likely to die and almost four times as likely to be injured. For SIWs, the rate ratio was 0.3 for fatal injuries and 1.4 for nonfatal injuries. That is, younger victims were less likely to die but slightly more likely to be injured. Although black residents were overrepresented as victims, especially for GSWs, the CFR was higher for white GSW victims (25% vs 15%). There was no difference in CFRs by race/ethnicity for SIWs. These differences in CFRs suggest the need for additional research.

Conclusions

Statewide surveillance of weapon-related injuries is feasible and can provide important new insights on the epidemiology of these injuries. With the first year of statewide WRISS data, we are beginning to uncover important differences between fatal and nonfatal injury rates and differences between communities. In some areas--for example, victim-offender relationship and circumstance--surveillance data are suggestive, but because of high levels of missing data, are difficult to interpret. Basic surveillance may need to be supplemented in these areas by more targeted, in-depth studies. On the other hand, surveillance data are very useful for identifying community-specific risks.

WRISS is embarking on a new phase which includes linkage with additional data sets, including hospital discharge and mortality data. Through data linkage and statewide surveillance, we hope to be able to provide additional information about the cost and potential long-term medical effects of weapon-related injuries. Data over time also will be useful for the evaluation of community-specific interventions.

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FIREARM INJURY REPORTING, SURVEILLANCE, AND TRACKING SYSTEM (FIRST)

Jennifer J. Balogh, Contra Costa Health Services Department

Paper not available for publication.

YOUTH AS VICTIMS OF HOMICIDES: PREVENTION OF CHILD HOMICIDE WITH AN INTERDISCIPLINARY YOUTH FATALITY REVIEW TEAM

Chukwudi Onwuachi-Saunders, Philadelphia Health Department

Patricia West

Dawn Berney

Philadelphia is the fifth largest city in the United States and has an estimated population of approximately 1.6 million people. Philadelphia has been impacted by violence in many ways. The residents have all suffered because of this problem. Therefore, the city of "brotherly love" created a community-based, public/private, peace promotion/ violence reduction, initiative known as Operation Peace in Philadelphia or O.P.P designed to address this issue.

The vision for this initiative is that by the year 2000, there will be a significant reduction in violent behaviors, preventable deaths and disabilities, and an enhanced quality of life for all residents. The mission is to establish new ideals, beliefs and lifestyles for all Philadelphians as it relates to interpersonal violence.

The initiative consists of three components: 1. a community collaboration made of action teams charged with development, implementation, and evaluation of prevention strategies; 2. a long-term media/awareness campaign; and 3. an innovative information (data) system. This third component is to help enhance research and evaluation. It encompasses the Philadelphia Interdisciplinary Youth Fatality Review Team (PIYFRT).

The Philadelphia Interdisciplinary Youth Fatality Review Team represents a comprehensive effort to enhance the research of interpersonal violence involving youth. The PIYFRT may be the only death review process in the nation which is also a major component of a city's violence prevention initiative. It may also be the first child death review team in the nation with a subcommittee focusing on youth homicides.

The mission is to prevent future child deaths by review, analysis and subsequent initiation of corrective action. The PIYFRT is modelled after the child death review process (1). Child Death Review Teams are routine, systematic, multi-agency, multi-disciplinary processes. They begin collecting and organizing diverse data, in order to develop policies that will have measurable impact on the problem of youth fatality. The PIYFRT also focuses on unintentional and natural deaths of youth.

The members of Philadelphia's youth homicide subcommittee include representatives from the Health Department, the Office of the Medical Examiner and its Grief Assistance Program, the police and fire departments, the District Attorney's Office, Family Court, the Department of Human Services, the school district, two major community-based organizations: the Philadelphia Anti-Drug Anti-Violence Network and Congresso de Latinos, and local hospitals. This collaboration recognizes that no one agency or organization has the capacity to chronicle all the circumstances surrounding the lives of those involved in youth fatalities.

The subcommittee meets once a month to review homicides of persons 21 and under. The committee members share information from their respective agencies in order to complete the data form (Appendix A & B). The database includes variables depicting the victims, offenders, and their families, thus permitting a clearer understanding as to how and why the deaths occurred. After consideration of the data, the determination is made as to which deaths are "preventable" and subsequently what policy strategies should be implemented or enforced to prevent its reoccurrence.

A "preventable" death is one in which, with retrospective analysis, it is determined that with a reasonable intervention the death might have been prevented. Reasonable is defined as taking into consideration the condition, circumstances or resources available.

In 1994, Philadelphia had 113 homicides to youth 0-21 years of age. Homicides represented 20% of all deaths to youth in this age category. Of these homicides, 79.6% were to African-American males between the ages of 16-21 years. (figure 1) Seasonal patterns were not evident although August had the lowest number of deaths. Time of the injuries was unknown for 32%, but (71) 63% occurred between 3 P.M. and 6:59 A.M.

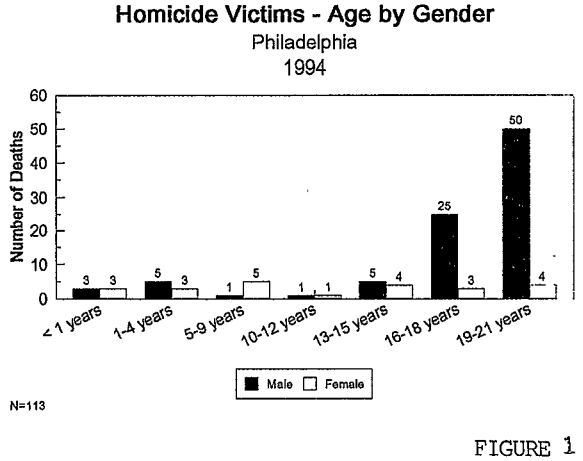

FIGURE 1

Preliminary in depth analysis had only been completed on 62 deaths occurring between January 1--June 30, 1994. Fifty-three percent of these homicides occurred on the streets. For 56.5%, the relationship between the victim and offender was unknown (figure 2). Known offenders had the same racial/ethnic classification as their victim's, 14.5% acquaintances and 4.8% friends. Circumstances for the deaths were unknown for 40.7%. The second leading cause was arguments 25.4%. Firearms (77.4%) were the leading weapons (figure 3).

Of the 62 deaths only 37.1% were determined to be "preventable" while 16.1 % were not "preventable." For 46.8% (29) it was unknown whether the death could have been prevented. The leading cause for unknown "Preventability" was missing information (figure 4).

Future analysis will yield:

- -type and number of agencies with prior knowledge of victims and perpetrators.
- -age of victim at contact with agencies.
- -school problems, etc., etc.

Youth in Philadelphia appear to be susceptible to many of the same risk factors for interpersonal violence highlighted in the literature (2,3,4,5). However there remains many unknown variables. Collecting and examining data on youth homicide victims with an interdisciplinary youth fatality review team will obtain more information than with death certificates or single agency reporting alone. This type of database will highlight risk factors many young victims, perpetrators and their families' experience which may make them more susceptible to interpersonal violence.

Our recommendations thus far include:

1. **Age groupings should be done with caution.** Combining 15-19 year old youth (for other than convenience) may be nothing more than implicating younger youth for older youth behavior. A 15 year old's psychological and physical development is different from that of a 18 or 19 year old. In the United States, 18 year olds are considered to be adults and therefore may exhibit adult behavior, i.e., interpersonal violence.

2. **When determining the relationship between victim and perpetrator, there is a need to clearly define a friend from an acquaintance.** For many of our youth there is a distinct difference between a friend and an acquaintance. This distinction has an impact on behavior. Therefore this type of information will benefit and augment prevention strategies, e.g., conflict resolution curricula.

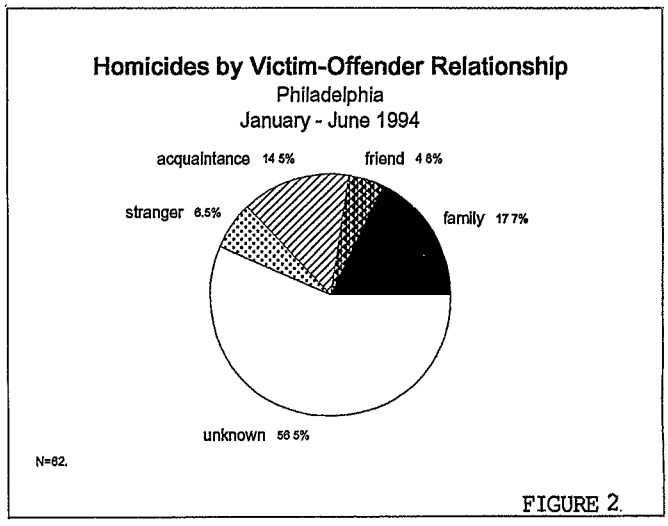

FIGURE 2.

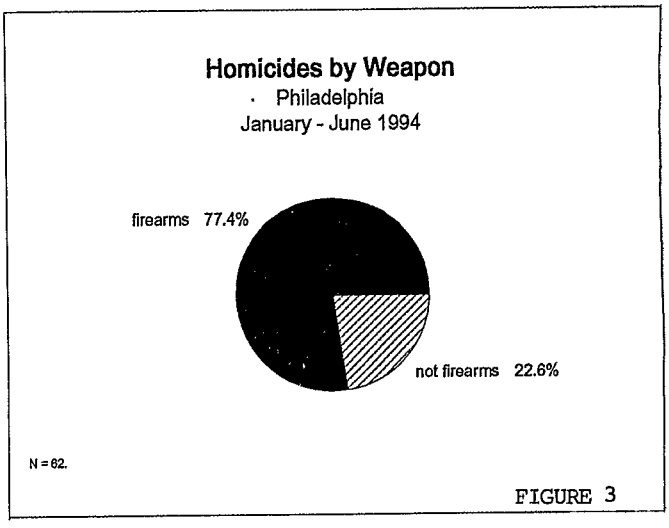

FIGURE 3

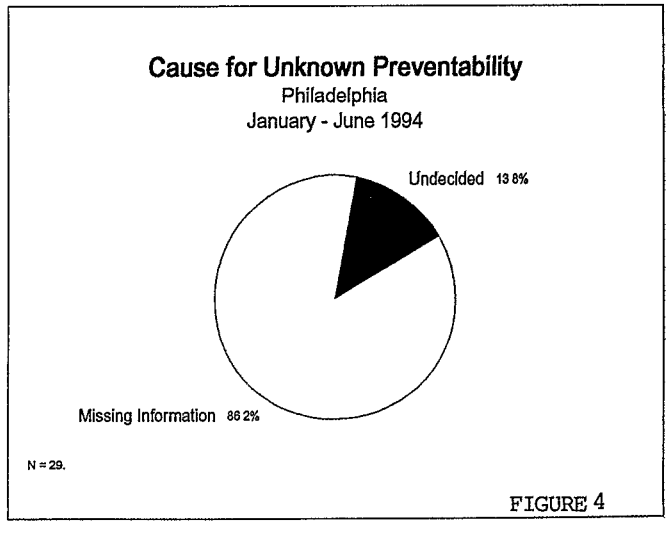

FIGURE 4

3. **Policies should be enforced to ensure that "missing information" is not accepted on the local level.** This process has revealed that even with multiple agency input it is difficult to obtain all the information needed to fully understand the problem.. This has far-reaching implications for state and national level reporting, specifically highlighting causality or risk factor identification.

Undertaking this routine systematic and inexpensive research process allows the expansion of knowledge to determine "preventability". "Preventabilitya" with subsequent policy development, will assist communities to implement necessary changes that will ultimately prevent youth from becoming victims of homicides.

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PHILADELPHIA INTERDISCIPLINARY YOUTH FATALITY REVIEW TEAM HOMICIDE SUB-COMMITTEE

1. Cert. #: _____

Decedent Background

2. MEO #: _____

3. Name: _____ 4. Age: _____ 5. DOB: _____ 6. DOD: _____

7. Address: _____ 8. City: _____ 9. State: _____ 10. Zip : _____

11. Ethnicity: _____ 12. Race: _____ 13. Gender: a. male b. female

14. Cause of death: _____ 15. Address of Event: _____

16. Date of event: _____ 17. Approx. event time: _____ a.m. p.m.

18. Death certificate adequate? 1. yes 2. no 3. unknown 19. Problem with Death Certificate? _____

20. Certifier:: 1. MD 2. ME 21. Autopsy? 1. yes 2. no 22. Where employed? (if applicable) _____

Report from MEO:

23. Body part affected: 1. head 2. trunk 3. extremities 24. Prior weapon-related injuries? 1. yes 2. no

25. Toxicology investigation? 1. yes 2. no 26. Significant tox findings? 1. alcohol 2. drugs _____ 3. none

Report from P.D. # _____

27. Homicide random? 1. yes 2. no 3. unk.

28. Perpetrotor/susp. perpetrator identified?
1. yes 2. no 3. unknown

29. Number of perpetrators: _____

30 Circumstances of **homicide:**
1. argument 2. gang activity
3. felony (other crime) 4. self defense
5. drug related 6. domestic violence
7. child abuse 8. arson
9. playing w/ guns 10. retaliation for event
11. reverse felony 12. other
13. crossfire 99. unknown

31. Method used:

Firearm	Non-firearm
1. handgun automatic	7. knife
2 non-auto.-revolver	8. fists
3. shotgun	9. poison
4. rifle	10. other: _____
5 other _____	
6. unknown	

32. Place of event:
1. highway/street 2. own residence
3. other residence 4. school property
5. victim's workplace 6. bar/club/tavern
7. recreation area 8. other _____
9. unknown 10. vehicle

33. Was parent/parent sub. identified as perp?
1. yes 2. no 3. unknown

34. Did the perpetrator ever have responsibility for care or supervision of the child (e.g. baby-sitter or teacher?)
1. yes 2. no
3. unable to determine

35. Relationship of perpetrator to the victim?
1. parent/guardian 2. parent paramour
3. spouse, paramour
4. ex-spouse, ex-boyfriend/girlfriend
5. grandparent 6. aunt or uncle
7. friend 8. acquaintance
9. baby-sitter 10. stranger
11. self 12. other _____
13. unknown 14. other relative

Report from DHS

36. Number of siblings living in home of deceased child? _____

37. Deceased has living children?
1. yes 2. no 3. unknown

38. Was DHS notified of death?
1. yes 2. no 3. unknown

39. Who was legally responsible for the care of the deceased child?
1. Mother 2. Father
3. Grandparent 4. Aunt or Uncle
5. Foster parent 6. Other

40. Who was primary caretaker?
1. Mother 2. Father
3. Grandparent 4. Aunt or Uncle
5. Foster parent 6. Parent's paramour
7. Parent's neighbor 8. Other

41. Is a parent in prison? 1. yes 2. no

42. Was victim in contact with a .s.s a.?
1. yes 2. no

43. Which agency?
1. food stamps/Medicaid
2. counseling agencies
3. other agency _____
4. none

44. Age when first in contact with s.s.a.? ____

45. Which CBO in contact with?
_____

46. Was there a DHS investigation of this death?
1. yes 2. no 3. unknown

47. DHS action resulted:
1. case substantiated 2. not substantiated
3. undetermined/ unk 4. other - explain

48. DHS investigation of surviving children?
1. yes 2. no 3. unknown

49. Court involved with siblings or other family members as a result of this death?
1. yes 2. no 3. unknown

50. Has victim had relationship with grandparent?
1. Yes 2. No

51. Victim (V) /Family history (F): (choose any of the following, if applicable)

1. diagnosis or treatment for severe mental health problems	V	F
2. victimization in domestic violence	V	F
3. perpetrating domestic violence	V	F
4. vict. of child abuse/neglect -- phys.	V	F
5. victim of child abuse -- sexual	V	F
6. prior reports to DHS for child abuse/neglect	V	F
7. perpetrating child abuse/neglect	V	F
8. substance abuse that interferes with ability to perform daily tasks.	V	F
9. prior arrests/dispositions/ convictions for any crimes	V	F
10. contributing medical problems	V	F
11. school problems	V	F
12. employment problems	V	F
13. CBO contact	V	F
14. homeless - currently	V	F
15. homeless - ever	V	F
16. frequent moves	V	F
17. lost someone in violent death	V	F

School history

52 School history - circle all that apply
1. truant 2. poor grades
3. learning disabled 4. behind in grade
5. change schools 6. discipline prob.
7. dropout 8. expelled
9. ADHD 10. special ed.
11. no problems 12. unknown

53. Present grade in school _____

54. Age of dropout _____

GAP Information

55. Religious affiliation: _____

56. Were there kids who witnessed the homicide?
1. yes 2. no 3. unknown

57. Which services will be provided?
_____

58. Was victim a witness to prior crime event?
1. yes 2. no 3. unknown

APPENDIX A

Court Information - Victim

59. At time of event - current legal status with justice system?
1. bench warr. 2. on probation 3. arrest warr.
4. completed 5. none

60. Involved in drug trafficking?
1. yes 2. no 3. unknown

61. Juvenile record:
Age Charge Outcome

62. Placed in youth residential facility?
Name: Age Length of Placement

63. Adult record:
Age Charge Outcome

64. Placed in adult correctional facility?
Name: Age Length of Placement

Perpetrator Information:

65. Name: _____

66. Address: _____

67. City: _____ 68. State: _____

69. Zip code: _____ 70. Age: _____

71. Ethnicity: _____

72. Race: _____

73. Gender: 1. male 2. female

74. Perpetrator (P) /Family history (F):
(choose any of the following, if applicable)

	P	F
1. diagnosis or treatment for severe mental health problems	P	F
2. victimization in domestic violence	P	F
3. perpetrating domestic violence	P	F
4. victim of child abuse/neglect – physical	P	F
5. victim of child abuse – sexual	P	F
6. prior reports to DHS for child abuse/neglect	P	F
7. perpetrating child abuse/neglect	P	F
8. substance abuse that interferes with ability to perform daily tasks.	P	F
9. prior arrests/dispositions/convictions	P	F
10. contributing medical problems	P	F
11. school problems	P	F
12. employment problems	P	F
13. CBO contact	P	F
14. homeless - currently	P	F
15. homeless - ever	P	F
16. frequent moves	P	F
17. lost someone in violent death	P	F

75. Parent in prison?
1. yes 2. no 3. unknown

School history

76 School history - circle all that apply
1. truant 2. poor grades
3. learning disabled 4. behind in grade
5. change schools 6. discipline prob.
7. dropout 8. expelled
9. ADHD 10. special ed.
11. no problems 12. unknown

77. Present grade in school _____

78. Age of dropout _____

Court Information

79. Was case presented to the prosecutor?
1. yes 2. no 3. unknown

80. Criminal charges pursued by prosecutor?
1. yes 2. no 3. unknown

81. Outcome of court activities, (if known)?

82. Involved in drug trafficking?
1. yes 2. no 3. unknown

83. At time of event - current legal status with justice system?
1. bench warr. 2. on probation 3. arrest warr.
4. completed 5. none

84. Juvenile record:
Age Charge Outcome

85. Placed in youth residential facility?
Name: Age Length of Placement

86. Adult record:
Age Charge Outcome

87. Placed in adult correctional facility?
Name: Age Length of Placement

88. Mental Health Assessment 1. yes 2. no

89. Death investigation adequate?
1. yes 2. no 3. unknown

90. Is this death **preventable**? 1. yes 2. no
3. unknown (incomplete information)
4. unknown (unable to decide)

91. If no, missing elements are?

92. Tracking pending information:
1. autopsy report 2. toxicology report
3. school reports 4. district attorney
5. medical records 6. AID records
7 DHS information 8. CBO history
9. MH/MR history 10. Substance Abuse treatment records
11. Other

93. Prevention strategies/policy implications _____

94. Comments: _____

APPENDIX B

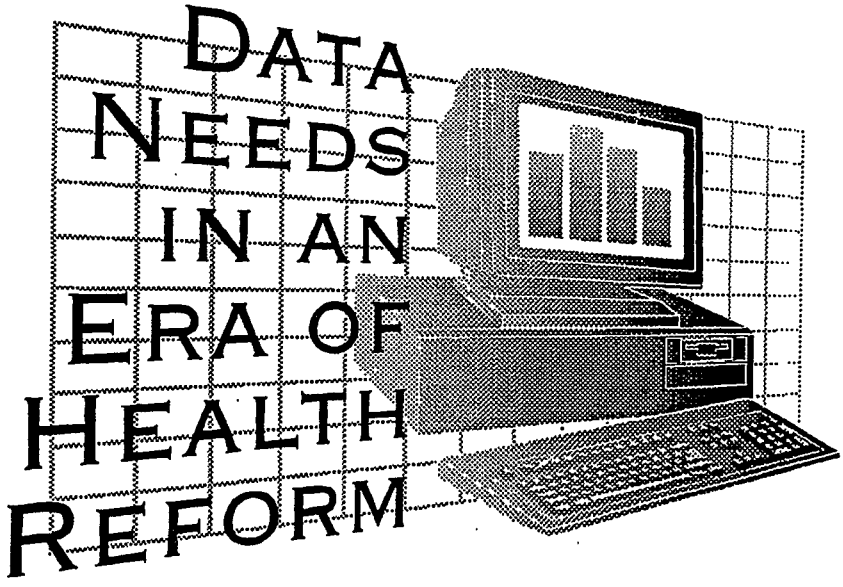
VIOLENCE IN THE WORKPLACE: NUMBERS, RATES, RISK FACTORS, AND PREVENTION STRATEGIES

E. Lynn Jenkins
National Institute on Occupational Safety and Health

Paper not available for publication

Session B

Methods for Small Area analysis



NEIGHBORHOOD HEALTH STATUS REPORTING: IMPROVING THE UNDERSTANDING OF LOCAL PUBLIC HEALTH NEEDS

Karen L. Power, Boston Department of Health and Hospitals

Paper not available for publication

DEMAND FOR GENERAL PRACTITIONER SERVICES - A PRACTICAL TEST OF SYNTHESISED ESTIMATION

John Charlton, Office of Population Censuses and Surveys, London, WC2B 6JP, UK.
Patrick Heady, Gerry Nicolaas

Abstract

Synthesised estimation techniques are methods for obtaining local estimates by combining data which are not available for local areas with other data which are. For example, we may wish to produce estimates combining national survey data with electoral ward data available from a census. Usually the opportunity to evaluate the performance of such estimates does not arise, but owing to the existance of a unique dataset OPCS has been able to evaluate estimates for two different measures at two different area levels - populations of 200,000 and 500 respectively. The estimates of serious illness for the larger areas correlate well with mortality rates for the same areas, providing some evidence of their validity. A simulation exercise was undertaken for the smaller areas to validate estimates against actual rates. Although the estimates are not accurate for individual areas, they represent a substantial improvement over assumptions of equal consultation rates which would otherwise have to be made. The same methods could be used to obtain other estimates of relevance to the health services.

1. Introduction

Synthesised estimation techniques are methods for obtaining local estimates by combining data which are not available for local areas with other data which are. For example, we may wish to produce estimates combining national survey data with electoral ward data available from a census. National survey data typically provide unreliable direct estimates for areas smaller than fairly broad regions. Synthesised estimates use the whole national data set to produce estimates of how the variable of interest, for example health status, relates to other characteristics of the individuals in the sample (such as age, sex, housing tenure and ethnic group) and to characteristics of the areas in which they live (e.g. rural/urban neighbourhoods). A mathematical model is developed that is used to 'spread' the information about the variable of interest to local areas throughout the country, producing model-based estimates of the values to be expected. Anyone applying survey results to local situations is in effect producing some form of synthesised estimates, although they may not be aware of the technical term. There has recently been an increased interest in small area estimates as a result of the need for more careful planning, and new techniques, many of which draw upon nested multilevel modelling have been developed[1]. Little work has been done, however, on assessing how well the estimates perform when compared with reality. In this paper we have taken the opportunity to conduct practical tests on the performance of the estimates, using a particularly useful large data set.

The study had two parts designed to address two different questions regarding the reliability of synthesised estimates.

Study (a) produced estimates of the prevalence of serious illness for some 250 medium sized areas of England and Wales (around 200,000 population each), and compared these estimates with mortality in a slightly wider age group.

Study (b) was a simulation exercise to investigate how accurate synthesised estimates are at the really small area scale, and whether model-based confidence intervals could be relied on. It was based on areas of around 500 population (200 households), and employed a simple model with simplifying model assumptions. Thus in many respects it would resemble a 'worst case'. The modelling was based on a sub-sample of the MSGP4 data to achieve a sample size more typical of most sample surveys.

2. Data Sources

2.1 The 4th National Study of Morbidity in General Practice, 1991-92 (MSGP4).

In the United Kingdom there is a system of universal patient registration with GPs, and nearly all residents have their health care managed via the practice with which they are registered. Apart from medical emergencies, secondary care is achieved through referral by general practitioners. Following discharge, relevant morbidity data are forwarded from hospital to practices. Thus the general practice provides the ideal setting for measuring health status as encountered by the medical profession. Corresponding denominators are provided from the practice age/sex registers. The survey data in our study comes from MSGP4[2], a study which collected data on all face to face contacts between 502,493 patients and their general practitioners

throughout England and Wales between 1 September 1991 and 31 August 1992 - providing data on 468,042 patient-years at risk. The 60 practices taking part in the study were not randomly selected, since they had to volunteer to take part in the survey, and have the necessary computer systems to collect the information required. They were selected from volunteers to achieve the best possible national coverage, including practices from all Regional Health Authorities and with diverse socio-economic characteristics. Doctors recorded their diagnoses on computer using the Read coding thesaurus which is in general use in the UK. There could be any number of diagnoses per contact, and these were subsequently mapped to ICD9 by OPCS. In addition a linked interview survey was conducted to collect socio-economic details concerning the patients. This survey achieved 83 per cent coverage. The socio-economic data were similar in distribution to that recorded for England and Wales in the 1991 Census.The data thus enabled prevalence, incidence, and health utilisation measures to be calculated for different socio-economic groups, and provided near saturation coverage of the immediate locality of the practice in about half of the general practices taking part in the study, thus making it possible to know the true consultation rates for a number of small areas.

2.2 The Two per cent Sample of Anonymised individual census Records from the 1991 census (SAR).

The 1991 census sample of anonymised records is described fully elsewhere[3], and was the source of most of the local data used to spread the survey results to medium sized areas of England and Wales (study a). It provided precise information for all the socio-economic items apart from smoking prevalence, which was estimated from General Household Survey[4] figures for the region in which the medium sized area was situated. There are 253 SAR-areas identifiable, corresponding to local authorities, or in the case of very small authorities, to two or more adjacent authorities combined. The sample for each area was approximately 4,000, out of a population of around 200,000.

3. Study (a): Estimates for medium size areas, with cross-validation against independent data.

3.1 Methods

The variable of interest was the proportion of people expected to consult for serious illness, ie any condition that was life threatening, requiring major surgery or intensive care, or having the potential for serious complications or recurring disability. Because different models might be required for different age/sex groups, separate models were fitted for males and females for the age groups 0-15, 16-44, 45-64 and 65 and over. In this paper we concentrate only on the model for men aged 16-44. The other results, and a fuller explanation of the modelling, can be found in the study report[2].

The probability of consulting for a serious illness was treated as a binomial variable and modelled using GLIM4[5].The following socioeconomic variables were analysed in relation to the variable of interest: age (single years); ethnic group; housing tenure; social class; economic position (eg whether unemployed); whether in practice for full year; family type (combining marital/cohabiting status with having children); smoking status; whether living in a rural or urban locality (Department of Environment classification of enumeration districts); crow-fly distance from practice; and general level of limiting long-term illness in the locality of residence (1991 Census). The number of days that a patient was at risk of consulting was explicitly included in the model as an 'offset'.

The model was a multi-level one, with practice as a first level and patient as the second level. Practice variations were explicitly allowed for by fitting a separate practice constant for each practice (as a 'fixed effect', since the practices were not a random sample). This allowed for the possibility that each practice would have its own level of recorded morbidity, over and above that which was due to patient characteristics. In the event the between-practice variations proved to be greater than the variations due to socioeconomic characteristics.

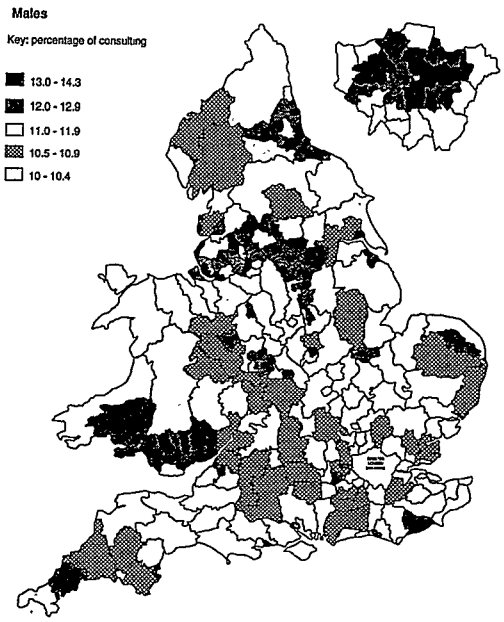
3.2 Results

The resultant multivariate logistic regression model provided an estimate of the probability of consulting for serious illness for individuals with any combination of the characteristics used in the model. In order to calculate the estimated consultation rates for each SAR-area, we used the parameter estimates derived from this model to calculate individual consultation probabilities for each of the 4,000 people in the SAR-sample for each area. The synthethised estimate of the area's prevalence was then the mean of these rates.

The map (Figure 1) shows how the estimated probability of consulting for serious illness by men aged 16-44 varied between different parts of the country. The pattern was much as would be expected. In order to cross validate the results these estimates were compared with an independent measure,

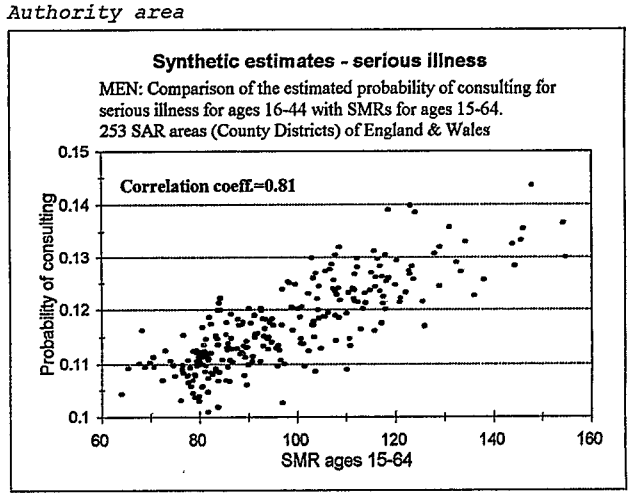
age standardised mortality ratios for ages 15-64.

Figure 1: Synthesised estimates of the percentage of males aged 16-44 consulting their general practitioner for serious illness, based on the MSGP4 survey and the 2 per cent sample of anonymised individual records from the 1991 census. Local Authority areas of England and Wales.



It had been hypothesised that serious illness in ages 16-44 should be correlated with mortality in the somewhat wider age band 15-64. Figure 2 shows the relationship between the two measures, which was linear, with a correlation coefficient of 0.81. This provides some reassurance that the estimates of serious illness rates are valid ones. An independent analysis, for females in this age group, gave similar results[2].

Figure 2:Comparison of the estimated proportion of men aged 16-64 consulting for serious illnes, with SMRs for men aged 15-64, by Local Authority area



4. Study (b) Estimating consultation rates for very small areas - confidence intervals.

4.1 Methods

Enumeration districts (EDs) were chosen as the areas for which estimates were to be made. These are the smallest areas for which OPCS provides information about population characteristics. They consist of approximately 500 individuals, or 200 households. The aim was to estimate how consultation rates (for any reason) differed from the average for the practice as a whole.

To approximate the synthesised estimation process as it would apply for a sample survey, the modelling was based only on a subsample of the MSGP4 data. In addition, the dataset analysed was restricted to those EDs for which the MSGP4 achieved 70 per cent coverage or better. This dataset comprised 228 EDs in 38 of the original 60 practices (for 9 of the 38 practices the dataset contained only 1 ED, for the remaining 29 there were 2 EDs or more). The reason for restricting the data to these EDs was so that we could know the true consultation rates, and also estimate them for comparison. For the purpose of the simulation exercise the sampled individuals in the 228 EDs were taken to be the true population, and each ED's socio-economic characteristics were derived from the MSGP4 data rather than from the census itself. The only exceptions to this were the percentage with a limiting long-term illness, which was taken from census data because it was not covered by the MSGP4 study, and the urban/rural classification.

The following variables were included in the analyses:

i) The number of consultations for any

reason was taken as the dependent variable. The objective was to estimate the difference between the mean consultation rate for an ED and the average for the practice.

ii) Patient level data comprised: age and sex; single; married or cohabiting; widowed, separated or divorced; White; Indian, Pakistani or Bangladeshi; Black or other; owner occupier; renting accommodation; working; not working.

iii) ED level data (from the Census) comprised: percentage of inhabitants with a limiting long-term illness; urban or rural.

iv) Practice level data comprised: list size of practice; number of patients per principle in the practice.

The aim was to estimate the difference between the average consultation rate for each ED and the rate for the practice as a whole, ie we modelled the geographical variations within each practice locality.

We ran 10 simulations, each time dividing the practices into 2 sets: those that were used to fit the model (the model-fitting set); and those that were used to test the accuracy of the resulting estimates (the estimate-testing set). In each simulation practices were chosen with probability 0.5 for the model-fitting set (resulting in an average of 19 practices). The remaining 19 or so practices formed the estimate-testing set, but in fact only those practices with 2 or more EDs were used - since the objective was to assess the accuracy with which we could estimate differences between ED and practice means. For this reason the effective estimate-testing set contained on average about 109 EDs from 14 practices, although due to differencing from the practice means this resulted in only 95 or so *independent* point-estimates.

In order to fit the model, a subsample of 1 person in 8 was drawn from the model-fitting set, giving a sample of around 5,500 - similar to an ordinary survey size with 19 primary sampling units. The model was fitted using the ML3 [6] modelling program, using a generalised least squares method [7], and was a 3-level model (person, ED, practice), with fixed linear regression effects, and separate variance estimates for person, ED, and practice levels. The estimated variances of the random effects were combined to produce confidence intervals for the EDs, using the between-ED and the between-person variances from the multi-level model. This was done for the first 7 simulations only, due to time constraints. The proportion of intervals which contained the true value was noted.

Our approach was statistically fairly simplistic, for example we only took account of variances fitted by ML3 and not the variances of ML3's own parameter estimates. Similarily we have assumed normality where it is arguable that Poisson or Hypergeometric distributions would have been more appropriate. The reasons for sticking with simplicity were twofold - firstly that it was easier to implement. Secondly that if the test performs reasonably well with simple methods, then more sophisticated techniques would perform at least as well.

A final essential point to note is that in our procedures the data used to evaluate the estimates is almost entirely independent of the data used to derive the model parameters. The only element of dependence is that the choice of variables to include in the model was made on the basis of an initial regression analysis of data from all 38 practices in 228 EDs. The exercise thus provides an empirical test of the validity of the estimates which is almost entirely free from a priori assumptions.

4.2 Results

Table 1 shows the correlations between the true and estimated ED values for each simulation, ie ED differences from the practice mean. The values are consistent, ranging from a minimum of 0.58 to a maximum of 0.71 with a mean of 0.67. Figure 3 shows the scatter plot for the second simulation (whose correlation coefficient is also 0.67). It shows that the relationship between estimates and actual values is linear.

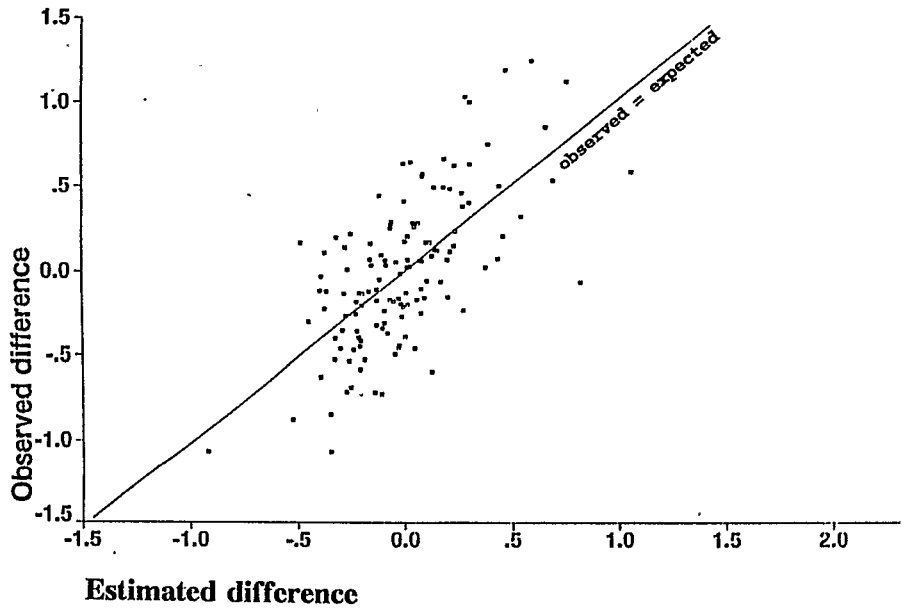
Table 1: Correlation between observed and predicted difference between ED average and practice average consultation rates.

Simulation	Correlation coefficient
1	0.71
2	0.67
3	0.71
4	0.68
5	0.58
6	0.66
7	0.63
8	0.69
9	0.70
10	0.65

Mean correlation: 0.67

Table 2 shows the performance of the confidence intervals for these estimates, in terms of the number of times that the true ED value fell outside the 95 per cent confidence interval. The mean percentage of values that fell outside the confidence interval (5.7) is close to the theoretical target of 5.0. Although the proportion was not at all stable, ranging from 0.0 to 12.0 per cent, the vari-

Figure 3: Difference between ED consultation rate and practice mean consultation rate: observed against expected (Simulation 2)



ability is not surprising. The number falling outside the interval is likely to approximate a Poisson variable with standard deviation equal to the square root of the expected number, which at about 6 is small. The clustered sample, together with the mutual dependence arising from differencing from the mean within clusters, will raise the variability compared with the simple random sample case.

Table 2. Percentage of predicted vaues outside the 95% confidence interval.

Simulation	Percent outside interval
1	6.0
2	7.0
3	0.8
4	6.9
5	12.0
6	0.0
7	7.2

Mean percent outside interval: 5.7

5. Discussion

Before reviewing the technical issues it is worth briefly considering the nature of the estimates in studies (a) and (b). Strictly speaking the dependent variable is behaviour - patient contact with their GP, which can be determined by patient and practice factors. Our models allow for both demand (patient characteristics) and supply (practice characteristics, or dummy practice variables), but the estimates of differences between areas depend entirely on the demand variables (the effect of supply has been removed). The value of such estimates to planners is as predictors of demand, and hence (often) need. Planners need to differentiate between smaller areas within some macro-area in order to make judgements about where to allocate resources.

The results presented above are encouraging because they show that it is possible to carry out this process at two levels:

- distinguishing medium size area with about 200,000 inhabitants within the context of national variation; and
- distinguishing EDs with about 500 inhabitants within an immediate locality (of a general practice).

The fact that the process works reasonably well for both examples suggests that it would probably produce useful results for areas of intermediate size (for example wards, with populations averaging 5,000). The fact that the confidence intervals worked well on average is also encouraging.

But does the estimation process work well enough? The answer depends on what one is trying to do. One criterion would be whether it is possible to place reasonably narrow confidence intervals around the estimates for individual areas. Although we have not superimposed confidence intervals around the scatter plots, a glance at the degree of scatter,

say for the ED estimates, would indicate that confidence intervals for any individual areas are likely to be wide. The ED estimates would certainly fail by this criterion. At this stage we cannot be sure about the width of confidence intervals for the SAR-level estimates, since the data structure did not permit us to calculate between-SAR variance. But the confidence interval criterion may not be the most appropriate in the context of health service planning. Although the estimate of resource demand for any individual area may not be very accurate, the synthetic estimates may still be valuable if on average they produce a better estimate of demand than would be obtained by simple proportionate allocation. The fact that the synthesised estimates account for a substantial proportion of the variation of the true values means that they would achieve this objective. Synthesised estimates may also be useful in another way - as an indication of the level of demand (or whatever) that would be expected on the basis of the characteristics that have been used to derive the estimate. Where alternative data sources exist relating to the actual outcome, these can be compared with the synthesised estimates to identify those areas whose outcomes are notably above or below expectations. By identifying these areas they may help in the search for additional factors, possibly relating to the local environment or policies. Thus for example general practices could compare their observed consultation rates with what would be expected independent of practice and local environmental factors.

It is important to note the obvious, that because synthesised estimates are based on a model, good estimates can only be produced when a good model has been developed linking the various data. Care needs to be taken in evaluating the appropriateness of the model to be used, and wherever possible the estimates should be evaluated against external criteria for face and other forms of validity.

Estimates useful to the health services could be produced from a wide range of surveys. While the MSGP4 can provide estimates based on contact with general practitioners, the Health Survey for England[8] and the General Household Survey (GHS)[4] contain information on contacts with other health service providers, and also health related behaviour. Surveys can be used to provide estimates of morbidity independent of health service contacts such as self rating of health, chronic illness, acute sickness, psychiatric morbidity, diet, contraceptive use, infant feeding etc. While OPCS does not have a specific programme of work in this area - the work we do is driven by demand from clients - we are keen to explore the applicably of synthesised estimation techniques to these other areas.

Acknowledgements

The authors wish to thank Professor Chris Skinner of Southampton University for his comments and advice

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COLLECTION AND UTILIZATION OF CHILD ABUSE STATISTICS IN AMERICAN INDIAN COMMUNITIES

Michelle Chino, Albuquerque Area Indian Health Board, Inc.

Public Health Research in Indian Communities

Public health research in American Indian communities involves many complex issues that may both help and hinder the development of an effective research methodology and the collection, analysis, and utilization of data. These issues include: 1) the unique strengths and diversity of Indian cultures; 2) the complicated relationships that exist between federal, state, and tribal agencies; 3) the vast distances between communities and services that exist in rural areas; 4) extremely limited human and financial resources; 5) overlapping and often conflicting legal and jurisdictional authorities; and 6) an array of social issues including poverty, substance abuse, modernization, and assimilation. Defining the parameters of any health issue requires a broad based understanding of the unique social, cultural, and political dynamics of Indian tribes and tribal communities.

Research and data collection must also take into account a tribe's status as a sovereign nation. The concept of sovereignty gives federally recognized tribes the right to exercise basic governmental powers. In addition, treaties, recent Indian legislation, and the US Trust responsibility mandate the Federal government to make provisions for basic needs such as health care, education, and housing. One result of this unique status is that, in any given tribal community, there may be a combination of tribal, federal, and state agencies providing services and collecting data. Each agency may have different roles, responsibilities, protocols for obtaining information, and levels of sophistication with regard to data management.

With few exceptions, the more than 500 Indian tribes and Alaskan Native villages in the US range in size from a few hundred to a few thousand people. While low population density does not preclude the existence of serious public health problems, it makes it difficult to document prevalence and incidence. In addition most, if not all, tribal groups are in some stage of epidemiological and demographic transition, reflected in part by the changing causes of morbidity and mortality among Indian people. This transitional status supports both the need for, and the opportunity for defining and addressing public health issues. For example, cross cultural studies have shown that societies in transition are especially susceptible to issues such as child abuse.

As federal budgets reduce and re-define the services available to Indian people, tribes are faced with the need to plan, develop, and fund their own prevention and intervention programs. The changing structure of the current health care system demands a new approach to addressing the unique needs of Indian people and the individual needs of tribal communities.

Child Abuse and Neglect

Child abuse is being increasingly recognized as a public health issue. This approach facilitates study of the history of the issue, insight into the complex bio-social processes at work, and the development of effective strategies for prevention and intervention. A public health approach also recognizes that the cultural, social, and political context of the community will determine what constitutes abuse; situations that excuse or mitigate abuse; appropriate responses that can be applied; and what the resources should be versus what is actually available. To fully comprehend and evaluate the issues that accompany research on child abuse and neglect among Indian people, it is necessary to understand the interaction between health and social services, Indian law, tribal culture, and the political systems that are both stressed, and called upon, when the breakdown of Indian family relationships result in the maltreatment of children.

In tribal communities the agencies involved in responding to the victim, the perpetrator, and the families include tribal, state, and federal health care services, social services, law enforcement, courts, and schools. Most Indian communities also have a designated Child Protection Team. This multidisciplinary team of service providers is designed to monitor and follow-up reported incidents of child abuse and ensure that available services are provided and are not redundant. Even so, which agency has primary responsibility for reporting and investigation and who has jurisdiction is rarely agreed upon. In addition, each agency requires varying types of data and information and may have varying levels of sophistication with regard to human and technological resources. With the current and impending changes in health care and related services, in order to develop or re-define the existing service delivery system, tribes need comprehensive yet simple methods that will maximize the availability and the utility of local data.

The National IHS Child Abuse and Child Neglect Project

The Indian Health Service (IHS) is a federal agency that is part of the trust relationship between tribes and the US government. The IHS provides primary and preventive health care services to a majority of reservation based tribal populations. The IHS has also been the primary source of health research and statistics for tribes.

A recent national level project (Chino et al., 1993) to address the issues of child maltreatment in Indian communities was part of the IHS research component. There were three objectives of the national project: 1) to research the scope and the long term effects of child neglect, physical and sexual abuse on Indian children; 2) to study the role of the Indian Health Service in issues of child protection and child maltreatment; and 3) develop a model intervention program. What started as an administrative assessment of policy and procedure however, rapidly became a study of risk factors, causation, resource utilization, family and community dynamics, local politics and response systems, and the severe gaps that exist between the administrative levels and services levels of the health care system.

Part of the initial intent of the project was to evaluate existing data, determine prevalence and incidence rates, assess variability between tribes, and make comparisons with data from the general population. This information, for the most part, simply did not exist. When information or data were available they were often limited in scope (e.g., only cases of sexual abuse were counted) and rarely in a format amenable to analysis (e.g., only aggregate counts).

The national level project was successful in obtaining caseload information on over 2000 incidents of child maltreatment from 37 tribal communities across the country. Although the data were not population based or truly representative of any individual tribe, the data set provided the first national level identification of variables

of interest and baseline estimates their impact. The process itself was invaluable in: understanding the constraints that inhibit effective data collection in tribal communities; developing comprehensive but simple analytic techniques; and identifying the need for tribal research to focus on community planning.

Barriers to Effective Data Collection

Surveillance issues (e.g., identification and reporting) had a major impact on data collection and continue to be a problem for many tribes. Issues include denial, the reluctance to recognize abuse, and the inability to separate abuse from poverty or cultural practices. In addition, despite federal mandates for reporting, many people are reluctant to report abuse. Sensitive issues such as child abuse can stigmatize individuals and communities which severely constrains the collection of data and hinders tribal communities from developing an aggressive, systematic response.

Data collection in tribal agencies is currently guided by the needs of the funding agency, usually at the federal level. While this ensures at least some data is collected at the local level, the format usually reduces its utility for agency and community planning and analysis. Even when information is available usage is constrained by: 1) a lack of a systematic, computerized system for data management within and between agencies; 2) varying levels of sophistication and ability; 3) reliance on personal knowledge of individuals and informal networks of communication; and 4) outdated equipment.

These barriers can be overcome by recognizing the limitations of local agencies; identifying cultural constraints on data collection and interpretation; convincing each community of the utility of a public health perspective and the concomitant modification of current data collection methods; and increasing local control over the information. Indian researchers are now considered vital to the development of epidemiological research projects in Indian communities. Indian researchers can serve as cultural liaisons between professional and lay communities. This is particularly important when research involves marginal populations, issues that are highly associated with fear and stigmatization, and where study in a clinical setting is difficult or impossible.

Development of Research Methods for Small Tribal Populations

As the system of health care for Indian people changes under current federal re-organization the need for planning at the community level is increasingly apparent. Programs planned at the national and regional levels do not effectively address local needs and priorities. However, until very recently, the IHS has been the primary source of program planning, program development, and program funding.

In order to justify the expenditure of federal funds for program development, the IHS requires calculated morbidity and vital event rates. These rates are rarely calculated below a regional level because, for small geographic areas, the number of events are often quite small. (The general consensus is that in small areas the number of events may be affected by yearly fluctuations which are purely random and a given rate in any one year may be very different from the true rate.) Although a small number of events may be insufficient for determining rates the events are significant to the local community and, proportionally, may have an enormous impact on health of the community and the direction of program planning.

Tribal communities need information that is adequate for identifying the scope of local health issues, sufficient for community feedback, and collected in a format that addresses not only multiple levels of need but the varying needs of different agencies. In addition, in small communities the process of obtaining and sharing information must avoid breaches of confidentiality on the individual level and avoid stigmatization on the community level.

The need for information goes beyond acquiring incidence and prevalence rates. If tribes are to be able to understand the scope of local issues and develop appropriate strategies for response they must be able to document not only the existence of a problem but contributing factors and related problems. This is best achieved by using an epidemiological approach to research and data collection.

Epidemiologic objectives, a natural result of a public health perspective, should set the requirements for study design and data analysis. Although statistical hypothesis testing is generally felt to be the preferred method for research, it is a mode of analysis that offers less insight into epidemiological data than alternative methods that emphasize estimation of interpretable measures. Compromises in study design or analysis cannot be defended in pursuit of a statistical goal or to use a statistical method that does not accomplish the study objectives. Communities need useable information that is relevant to local conditions. According to Rothman, 1986, the fundamental task is to quantify the occurrence of a public health issue, evaluate causal and sequelae hypotheses, and relate the occurrence to the community's social, cultural, and political context.

Analytical Issues

When rates are the issue numerators, denominators, confidence intervals, and statistical significance are key considerations. The confidence interval is the most common method used to assess the adequacy of an observed rate, as an estimation of its true value. The general rule for data sets is that rare events in small populations mean wide confidence intervals. The confidence interval is the most common method used to assess the adequacy of an observed rate as an estimation of its true value (D'Angelo, 1993). In general, a 95% confidence interval is defined as a 95% probability that the "true rate" is included in the interval. Since any rate based on fewer than 20 events in the numerator will have a 95% confidence interval about as wide as the rate itself, it is preferred not to calculate rates involving fewer than 20 events. The reality is that 20 events or less is common in small communities.

There are generally thought to be two options for increasing the numbers and thus narrowing the confidence interval: 1) combine several years of data; or 2) combine data from several smaller geographic areas into larger ones. The norm for the IHS is to combine three years of data at the Area (regional) level. This is sufficient to look for trends but not end up with misleading rates due to changing local conditions. The IHS doesn't report rates with small numbers because they are basically meaningless—as likely to be statistical noise as they are to be valid estimates. However an individual community finds its own numbers very useful. If these number can be presented in a simple but meaningful way, communities can not only begin to effectively address the problems but can also develop methods for future data collection and analysis.

There is also a third option—100% ascertainment, that is including every reported incident. With 100% ascertainment confidence intervals are not important and, whether the data are statistically significant or not is not the

point. What you have are actual numbers and a "true rate" that the community can understand and can use for planning purposes. This is much more important to tribes than statistical significance or statistical comparisons.

Although seemingly obvious for small areas, 100% ascertainment it is not always easily accomplished. With the involvement of multiple agencies, some degree of coordination and standardization of data collection is critical to increase precision and reduce random error. While the best way to increase precision is to increase the sample size, this is not realistic in small communities.

The alternative is to improve the design of the study to increase the efficiency with which information is obtained. With child abuse and neglect data, the local multidisciplinary child protection teams can facilitate this process. Because key response agencies are represented on the team, each can ensure that the needs of their agency are being met and that the data collection process is not an added burden to existing data collection. When planning is the focus, as opposed to calculating rates, the utility of 100% ascertainment, and the need for coordinated data collection, becomes apparent to tribal agencies.

The first step is to coordinate data collection between different agencies to ensure that all cases are included and that duplicates are removed. It may be necessary to simplify protocols so each agency, regardless of the sophistication of the data management system, can provide useful information. A data collection instrument specific to child abuse caseloads, and *Epi-info*, a statistical software program developed by the CDC, proved to be useful tools for some of the tribes.

It is also important to simplify the analysis and return a maximum amount of understandable information to each community as well as to the IHS area level. Bar graphs, and simplified analytic methods are easily understood and interpreted by tribal service providers and program planners. The ability to identify local trends and compare information with other area tribes is essential. By using a simple system compatible with the local level of sophistication and available equipment tribal communities can have information far more valuable than complex statistical analyses.

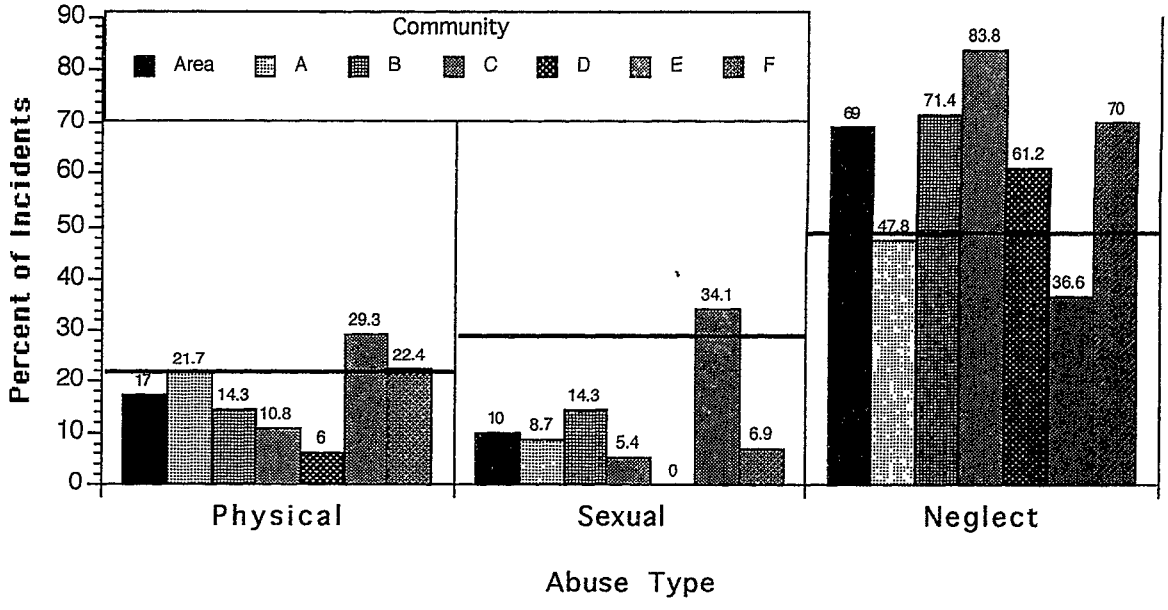
Results

A test of revised methods for data collection and small area analysis was conducted in one regional area and included 16 tribal communities. A data collection instrument was developed and information on all cases for a one year period were collected by local Child Protection Teams. The 16 communities reported a total of 379 incidents of child abuse and neglect. The number of cases reported ranged from a low of one case to a high of 79 cases. (Information from six of the communities, accounting for 287 incidents, are included in this report.)

"True" rates were reported back to each tribe along with descriptive information and a simple analysis. The information was also compared with an area aggregate and the national estimates from the IHS project. By presenting individual community and area data in a comparative graphic, local providers could assess the scope of local problems. The result was that the tribes finally had information that was useful for understanding local problems, comparing notes with other tribes, and an opportunity to assess the use of limited resources.

Although individual communities had the actual numbers to work with, comparing percentages between communities helped identify issues that may be unique to each community and issues that every tribe needed to address. In addition, in group presentations, percentages ensured the confidentiality of individual cases.

Figure 1. Percent of reported incidents by abuse type—comparison between six tribal communities, the regional area, and the national estimate



As indicated in figure 1, the type of abuse reported varied widely between communities. The black horizontal lines indicate the national level estimate; the first bar indicates the aggregate estimates for the area; and the other bars indicate the percent of the total number of incidents reported by each community by the type of abuse reported. The difference, whether statistically significant or not, helped individual communities assess issues such reporting biases which might account for numbers that were lower than expected, and risk factors that might account for numbers that were higher than expected. For example, the national estimate of sexual abuse is 28% of all reported cases. The combined average for all communities in the area was 10%. One community reported no cases of sexual abuse while another community reported 34% of all their cases were identified as sexual abuse. Each community felt the need to address the issue differently and a strategy based on either 28% or 10% would not likely have met the needs of either.

Some of the variables showed few if any differences. This was also very useful information because it confirmed the pervasiveness of certain risk factors. For example, figure 2 indicates that, for Indian children, home is the most likely location where abuse will occur. This was very important information for the tribes to have. Although local services providers have long known that child abuse is a family issue, national attention has been primarily focused on the abuse of Indian children in government schools. This level of information helped tribal agencies re-direct attention towards the needs of families.

Figure 2. Percent of reported incidents occurring at the victim's home—community, area, and national comparison.

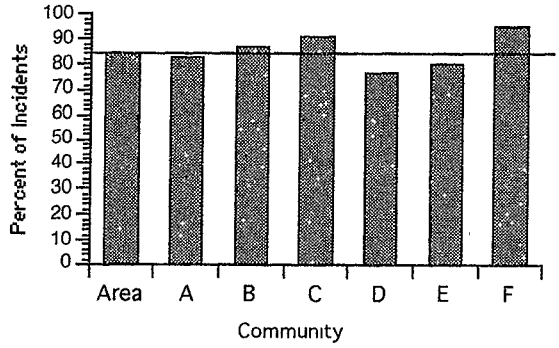
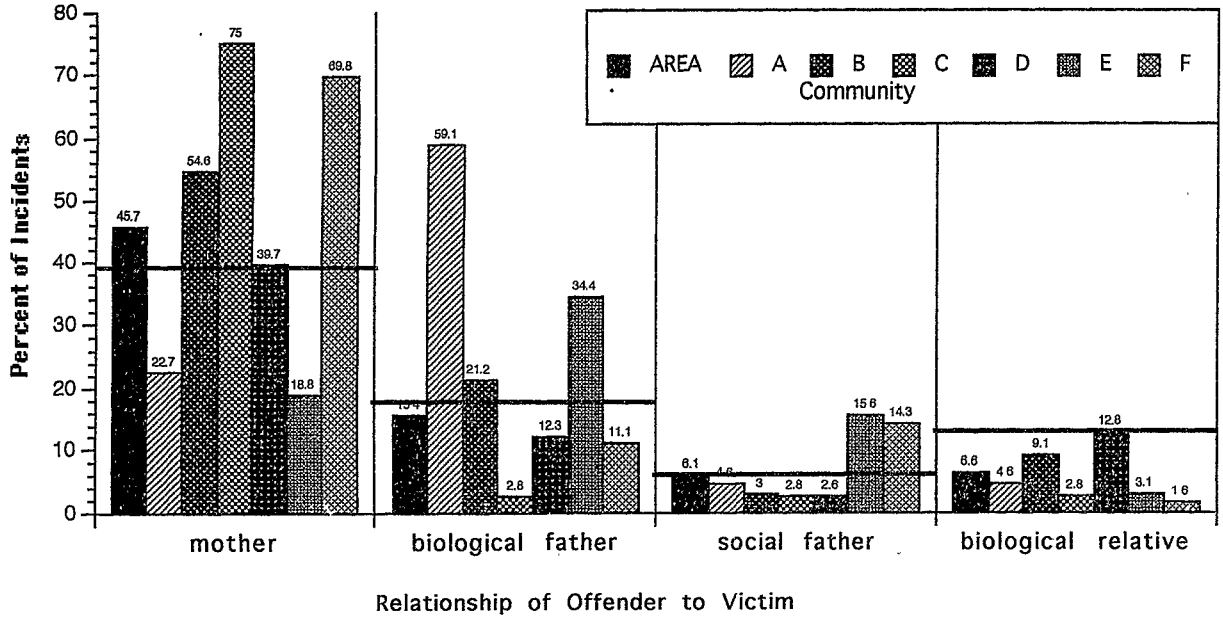


Figure 3 indicates the relationship between the victim and the offender for reported incidents. In general, parents and close biological relatives were identified as the primary perpetrators. Mothers were most often identified with incidents of neglect, fathers with incidents of physical abuse, and biological relatives with incidents of sexual abuse. Again this information was critical to focusing attention on the family and the extended family. Within each community, numbers that were higher than expected or lower than expected led to discussion of reporting issues, risk factors, and program planning.

Figure 3. Percent of reported incidents by victim-offender relationship—comparison of community, area, and national

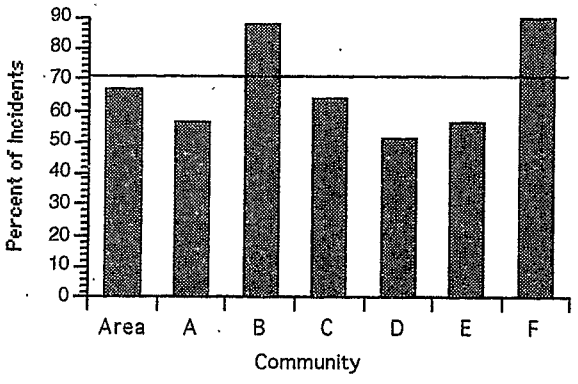


A major issue for Indian people is substance abuse. There was an assumption that all incidents of child abuse were the result of substance abuse. The data showed however, that while the correlation between perpetrator substance use and child abuse were higher for Indian people than for the general population, it was not a 100% correlation. If fact, the proportion of incidents involving substance abuse on the part of the perpetrator varied with the type of abuse, age, sex, and the relationship of the perpetrator to the victim.

As indicated in figure 4, while most of the communities were close to the national estimate (72%) and the area estimate (67%), the actual numbers of incidents involving substance abuse varied from a high of 89.9% to a low of 51%. Although substance abuse is a significant factor in incidents of child abuse in all the communities, some communities may need to more aggressively address the relationship between substance abuse and child abuse. This correlation also has indications for treatment and prevention.

The sum total of the data has had important implications for community planning and service provision at the local level. The information obtained through this process increased the tribes awareness of the issues, facilitated local level planning, justified requests for services from the IHS, and in combination, helped federal and state agencies guide planning and appropriations.

Figure 4. Percent of reported incidents involving substance abuse—community, area, and national comparison



Conclusion

The future of Indian health care is uncertain. The US trust responsibility to tribes and recent Indian legislation is in jeopardy. The Indian Health Service is facing regressive budgets and massive reorganization. Tribes need to be able to address public health issues in their communities. In order to accomplish this task, the current focus of data collection, methods of data analysis, and the of data need to be reconsidered.

In Indian communities the need for planning supersedes the need for statistical comparisons. When data on a large scale is available it can provide a "standard" by which individual communities can assess local problems but it can not be a substitute for local level information. Understanding similarities and differences between local and regional or national number help small communities prioritize issues and focus limited resources.

In order to obtain needed data, 100% ascertainment over a period of time can prove to be an effective means of evaluating the scope of local problems. While this may require coordination between agencies and redefining data collection protocols, the benefit of this approach for tribal communities includes community education and empowerment, better future planning, and a stronger focus on individual community needs.

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Acknowledgements

The National Indian Justice Center administered the contract for the national IHS project (#282-90-0036). The principal investigators were Ada Melton, Michelle Chino, and Lynne Fullerton.

Funding for the Area level project was provided the Albuquerque Area Indian Health Service, Divisions of Social Services. The principal investigators were Michelle Chino and Lynne Fullerton.

For more information about these projects please contact the author; the National Indian Justice Center, Petaluma, California; or the Indian Health Service, Office of Policy Evaluation & Legislation, Rockville, Maryland.

THE EVOLUTION OF PUBLIC POLICY AND STATISTICS: FUND ALLOCATION AND SMALL AREA ESTIMATION IN THE WIC PROGRAM

Allen L. Schirm, Mathematica Policy Research, Inc.
Cindy Long

1. INTRODUCTION

The Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) is a federal grant program for states and Indian Tribal Organizations (ITOs) that is administered by the Food and Consumer Service (FCS) of the U.S. Department of Agriculture (USDA). The program provides nutrition and health assistance services for low-income childbearing women, infants, and children. Pregnant and postpartum women and children under the age of 5 who have family incomes at or below 185 percent of the applicable poverty guidelines ($27,380 for a family of four as of July 1, 1994) are "income-eligible" to participate. To be fully eligible, participants must be determined to be at nutritional risk based on a medical and/or nutritional risk factor identified by a competent health professional. Persons exhibiting a medical risk factor (such as anemia, underweight, or diabetes) receive higher priority than persons at risk of inadequate nutrition.

WIC participants receive a federally-prescribed package of foods designed to meet their specific nutritional needs. For example, a WIC package for a newborn infant would consist entirely of infant formula, while a child's package would contain such items as milk, cheese, peanut butter, cereal, and juice. WIC participants also receive nutrition education and counselling and access to health and social services.

Research has demonstrated that WIC has been successful in reducing infant deaths, low birthweight, premature births, and other health problems. The program has also improved the nutrition and health care use of participants.

WIC is not an entitlement program--the number of participants in each year is limited by the funds appropriated. Funds are allocated among states based on two formulas established by regulation, one for food and one for administration and nutrition services. The food funding formula has been modified several times since the program's inception in the early 1970s to reflect changes in the size of the program and changing program priorities.

The size of the WIC-eligible population in each state has always been a factor in determining state WIC grants, and the availability of timely and accurate data on the number of women, infants, and children income-eligible for WIC has long been an issue of concern. However, the relative importance of these data and other components in the funding formula has varied over time.

President Clinton's first budget highlighted the expansion of WIC as a major priority, and set forth as a goal "fully funding" the program, that is, providing enough funds to allow all eligible persons who want to participate in the program to do so. The WIC program has already expanded significantly in recent years. From 1989 to 1994, annual WIC appropriation increases ranged from 9 to 12 percent per year. This program growth, coupled with the expected move toward full funding, prompted FCS to revise the funding formula in fiscal year 1994. This revision included a substantially increased emphasis on the eligibles data as a basis for funds allocation, and brought the need for timely and accurate data to the forefront.

2. EVOLUTION OF THE WIC FOOD FUNDING FORMULA

The WIC program was established in 1972, and for the first several years of operation, state grants were determined at the discretion of the USDA. In 1979, a food funding formula was formally established by regulation. This formula set forth two essential components that were the primary basis for food funds distribution until 1987. First, states were provided with their prior year funding level, plus some adjustment for inflation, assuming adequate funds were available. Any remaining funds were allocated based on a "growth" calculation, which attempted to direct funds to states on the basis of need for the program. Specifically, the formula considered each state's share of the estimated national population of income-eligible women, infants, and children, and its relative health status, as measured by the state's infant mortality rate and/or low birthweight rate relative to the national average.

The original 1979 funding formula placed equal weight on the income-eligibles data and the health data. However, in 1984, the formula was revised to place much greater emphasis on the income-eligibles data, increasing their weight in the growth calculation to a minimum of 80 percent (and in some cases much closer to 100 percent). This change reflected a belief that the eligibles data best indicated relative need among states.

In 1987, a major change occurred when a "targeting" component was added to the food funding formula. This component reflected concern that the limited WIC

funds be allocated based not only on the estimated need for the program, but also on states' demonstrated ability to serve those at highest risk. In proposing the new targeting component, USDA stated its concern that the existing funding formula did not discriminate between state agencies that had targeted this population effectively and those that had not. Thus, the 1987 regulation required that after stability grants were made, half of any additional funds be distributed based on states' shares of the national population of "high priority" participants (defined as women, infants, and children with a demonstrated medical risk). The remaining half was distributed based on the growth calculation (that is, using the states' shares of the eligible population and the state health indicators). States with well-targeted programs according to the new measure also received a larger inflation adjustment.

In 1994, USDA determined that several components of the 1987 rule had become outdated. In close consultation with the states, USDA concluded that the program had expanded so significantly that it was no longer necessary to provide incentives for states to serve those at highest risk. In addition, the targeting component was viewed as an obstacle to achieving funding equity among states. Thus, the 1994 funding rule eliminated both the participation-based targeting component, as well as the portion of the growth component that measured relative health status. The new rule stated that after stability grants had been provided, all remaining funds were to be allocated based on states' estimated shares of the national eligible population.

The new funding formula was structured to allocate any growth funds to states whose current resources were less adequate for serving their estimated eligible populations relative to other states. This is accomplished using a "fair share" concept. A state's fair share of available funds is its share of the estimated national population of persons eligible for the program. Thus, a state with one percent of the eligible persons has a fair share of one percent of total available food funds. States whose stability grants are less than their fair shares receive growth funds. The amount of growth funds received by an "under fair-share" state is directly proportional to the difference between the stability grant and the fair share. States with stability grants in excess of their fair shares do not receive growth funds (unless all the "under fair-share" states decline to accept the full amount of growth funds available).

3. WIC ELIGIBLES DATA FOR STATES

The establishment of the fair share component of the funding formula, combined with the rapid growth of the program, heightened USDA's concern about the quality of state eligibles estimates. Under previous rules, census data were specifically identified as the source for calculating states' shares of the eligible population. Data from the 1980 census were used from the early 1980s until 1994, when 1990 census data were used. WIC-eligible infants and children were estimated directly from census counts of infants and children at or below 185 percent of the poverty line. Income-eligible pregnant and postpartum women were estimated indirectly based on the counts of income-eligible infants.

The lack of timeliness of the census data was a longstanding concern, and the 1987 funding rule noted that the census data were flawed in this respect. However, no alternative data source was put forth. In the 1994 rule, no specific source of WIC eligibles data was identified in order "to allow for the use of the most timely and reliable data as it becomes available." In discussions with the states, USDA committed to place high priority on developing an alternative source to the census for the eligibles data. State WIC agencies desired improvements in the eligibles data not only for allocating funds, but also for using the data as a benchmark to assess program performance.

FCS, through contract research, undertook to develop a new methodology for estimating the population income-eligible for WIC in each state. The research focused on the Current Population Survey (CPS) as the likely alternate to the census for state-level income data. FCS identified several criteria for the state-level eligibles estimates, including: consistent methodology and data sources across states; an understandable, technically sound methodology; an ability to update the estimates annually and to capture year-to-year changes in states' relative positions; and the use of data that are as current as possible.

4. EVOLUTION OF THE ESTIMATION METHODOLOGY

The methodology for estimating WIC eligibles has evolved more slowly than the formula for allocating WIC funds. The first generation estimator, which used census data, was essentially unchanged from 1979 to 1994. It was just last year that a second generation estimator was implemented, although a third generation estimator is currently under development. The next three sections of this paper describe the first and second generation WIC eligibles estimators and briefly introduce the third generation estimator.

4.1 The First Generation Estimator

According to the first generation WIC

eligibles estimator, the current number of eligibles is the same as the number measured from the most recent census data available. Although census estimates are derived from large samples and, therefore, are precise, there was widespread dissatisfaction with the first generation estimator among policy analysts, WIC administrators, and advocates. They believed that census estimates were very inaccurate, failing to account for often rapidly changing economic conditions. According to census and CPS data, the recession of 1990-1991 was accompanied by a 20 percent increase nationwide in the number of eligible infants and children between 1989 (the year to which census income data pertain) and 1992. That increase, amounting to nearly 1.5 million infants and children, cannot be explained by population growth. The percentage of infants and children eligible for WIC rose by nearly 6 percentage points--from about 38 percent to 44 percent.

Such rapid growth in eligibles certainly creates difficulties for program planning and performance monitoring, key uses of WIC eligibles estimates. However, census data could still provide accurate estimates of fair shares for distributing program funds if the numbers of eligibles grew by the same proportion in every state. But, the recent growth in eligibles seems to have been spread very unevenly across the states. According to the 1990 census and the March 1993 CPS, the percentage of infants and children eligible rose between 1989 and 1992 by over 8 percentage points in Florida, New York, California, and New Jersey, but by under 3 percentage points in Massachusetts, Ohio, Michigan, and Pennsylvania.

These figures strongly suggest that by assuming nothing is changing over time, the first generation estimator may be badly biased. As an alternative to the census, the CPS provides the most timely data for developing annual state estimates of WIC eligibles. However, despite their timeliness, direct CPS estimates are imprecise because state samples of infants and children are small in all but a few states. This fundamental problem of small area estimation--the lack of data, that is, the small number of sample observations--led to the original adoption and continued use of the first generation estimator, an "indirect" estimator that "borrows strength" from the past. However, it seems that the gain in precision from using census data comes at the potential cost of substantial bias. Therefore, we sought an alternative estimator to minimize the tradeoff between bias from lack of timeliness and imprecision from lack of data. Based partly on the findings of Schirm (1994), who assessed the relative accuracy of several different estimators of state poverty rates, we began development of a second generation estimator that uses "shrinkage" methods.

4.2 The Second Generation Estimator

The second generation WIC eligibles estimator is a Bayesian shrinkage estimator that optimally averages CPS direct sample estimates and predictions from a regression model. As we will see, the shrinkage estimates obtained are more timely than census estimates, and substantially more precise than CPS estimates. This section describes our eight-step procedure for estimating the numbers of infants and children who were income eligible for WIC in each state in 1992. Additional technical details can be found in Schirm (1995).

Step 1: From the most recent census (1990), derive state estimates of the percentage of infants and children who were income eligible. Because the family income data collected in the census pertain to the preceding calendar year, the eligibility estimates are for 1989. We estimated the percentages, rather than the numbers, of infants and children who were income eligible to standardize for state population size.

Because census samples for states are very large, the estimates are precise. However, they quickly become "old" if economic conditions have changed substantially since the census.

Step 2: From the most recent CPS (March 1993), derive state sample estimates of the percentage of infants and children who were income eligible. The most recent CPS that has income data for families provides more timely information than the census. That CPS was the March 1993 CPS when we were developing eligibles estimates to be used in allocating funds for fiscal year 1995. Like the census, the CPS collects family income data for the prior year. Thus, the sample estimates pertain to 1992.

Although timely compared with the census estimates, the CPS sample estimates are relatively imprecise. The standard errors for the CPS estimates tend to be large, so our uncertainty is great. For example, according to widely used statistical standards, we can be confident only that the percentage of income-eligible infants and children in Delaware was between 22.5 percent and 41.6 percent. This range is so wide and our uncertainty so great because the CPS samples of infants and children in each state are small. Indeed, that is why we derived an eligibility estimate for infants and children combined, rather than separate estimates, one for infants and one for children. In the March 1993 CPS, there are data for fewer than 30 infants for most states.

Step 3: Construct sample estimates of the change in the percentage eligible

between 1989 and 1992. A sample estimate of the change in the percentage eligible between 1989 and 1992 was calculated by subtracting the census estimate for 1989 from the CPS estimate for 1992. We calculated sample estimates of change for use in the regression and shrinkage estimation described in the next few steps. Focusing on the change in the percentage eligible between 1989 and 1992, rather than just the percentage eligible in 1992, is a simple way to reflect a strong systematic relationship: states with a high percentage eligible in 1989 tend to have a high percentage eligible in 1992, and states with a low percentage eligible in 1989 tend to have a low percentage eligible in 1992. In principle, our shrinkage method obtains better estimates by using information on not only where a state "is," but also where it "began."

Step 4: Using a regression model, predict the change in the percentage eligible for each state based on observed changes in (i) Food Stamp Program (FSP) participation, (ii) Unemployment Insurance (UI) Program participation, and (iii) per capita income. The main limitation of the sample estimates derived in the previous step is imprecision. Regression can reduce that imprecision. Regression estimates are predictions based on nonsample or highly precise sample data, such as census and administrative records data. The latter include government program case files and vital statistics records.

Regression estimates are points on a regression line, a line obtained by regressing the sample estimates from the previous step on predictor variables. The three predictor variables we used measure the changes between 1989 and 1992 in (1) FSP participation, (2) UI Program participation, and (3) per capita income. These three were selected as the best predictors from a longer list. As expected, the estimated regression shows that states with relatively large increases in FSP and UI Program participation and large decreases in per capita income tend to have relatively large increases in the percentage of infants and children eligible for WIC. The standard errors for regression estimates are much smaller than the standard errors for sample estimates.

Comparing how the sample and regression estimators use data reveals how the regression estimator "borrows strength" to improve precision. When we derived sample estimates in Step 3, we used only data from Delaware to estimate the change in the percentage of infants and children eligible for WIC in Delaware, even though Delaware, like nearly all states, has a small CPS sample. Deriving regression estimates in this step, we estimated a regression line from sample and administrative records data for all the states and used the estimated line (with administrative records data for Delaware) to predict the change in WIC eligibles for Delaware. In other words, the regression estimator not only uses the sample estimates from every state to develop a regression estimate for a single state but also incorporates data from outside the sample, namely, data in administrative records systems. The regression estimator improves precision by using more data to identify states with sample estimates that seem too high or too low because of sampling error, that is, error from drawing a sample that has a higher or lower percentage of eligible infants and children than the entire state population has. For example, suppose a state had experienced stable FSP and UI Program participation and rising per capita income. Our regression estimator would predict a stable or declining percentage of eligible infants and children, implying that a sample estimate showing a large increase in WIC eligibles is too high. The regression estimate will be lower than the sample estimate for such a state. On the other hand, if the sample data for a state show a much smaller increase in eligible infants and children than expected in light of the observed changes in FSP and UI Program participation and per capita income, the regression estimate for that state will be higher than the sample estimate.

Step 5: Using "shrinkage" methods, average the sample estimates of change and the predictions of change. As noted, the limitation of the sample estimator is imprecision. The limitation of the regression estimator is bias. Some states really have larger or smaller increases in WIC eligibles than we expect (and predict with the regression estimator) based on changes in FSP and UI Program participation and per capita income. Such errors in regression estimates reflect bias.

These limitations arise for the following reasons. The sample estimator uses only sample data for one state to obtain an estimate for that state. It does not use sample data for other states or administrative records data. Although the regression estimator borrows strength, using data from all the states and administrative records data, it makes no further use of the sample data after estimating the regression line. It assumes that the entire difference between the sample and regression estimates is sampling error, that is, error in the sample estimate. No allowance is made for prediction error, that is, error in the regression estimate. Although not all, if any, true state values lie on the regression line, the regression estimator assumes they do.

Using all of the information at hand, a shrinkage estimator addresses the

limitations of the sample and regression estimators by combining the sample and regression estimates, striking a compromise. A shrinkage estimator takes a weighted average of the sample and regression estimates. We calculated weights using Bayesian methods, as described in Schirm (1995). Generally, the more precise the sample estimate for a state, the closer the shrinkage estimate will be to it. The larger samples drawn in large states support more precise sample estimates, so shrinkage estimates tend to be closer to the sample estimates for large states. Given the precision of the sample estimate for a state, the weight given to the regression estimate depends on how well the regression line fits, that is, whether we could find good predictors reflecting why some states have larger increases in WIC eligibles than other states. The shrinkage estimate will be farther from the regression estimate and closer to the sample estimate when we could not find good predictors and the regression line fits poorly. In contrast, the shrinkage estimate will be closer to the regression estimate and farther from the sample estimate when the regression line fits well. Striking a compromise between the sample and regression estimators, the shrinkage estimator strikes a compromise between imprecision and bias. The sample and regression estimates are optimally weighted to improve accuracy by minimizing a measure of error that reflects both imprecision and bias. By accepting a little bias, the shrinkage estimator may be substantially more precise than the sample estimator. By sacrificing a little precision, the shrinkage estimator may be substantially less biased than the regression estimator.

Step 6: Add the shrinkage estimate of the change between 1989 and 1992 to the census estimate of the percentage eligible in 1989 to get a shrinkage estimate of the percentage eligible in 1992.

Step 7: Multiply the shrinkage estimate of the percentage eligible by the state population of infants and the state population of children to get preliminary shrinkage estimates of the numbers of eligible infants and children. To obtain separate estimates for infants and children, we have assumed that the percentage of infants who were income eligible in a state is the same as the percentage of children who were income eligible, an assumption well-supported by census data. Our estimate of that percentage was obtained in Step 6.

To obtain estimated numbers from estimated percentages, we require state population estimates for both infants and children. The population estimates we used pertain to the resident population on July 1, 1992 and were developed by the U.S. Bureau of the Census from census and administrative records (mainly vital statistics) data. These estimates are often called "independent" estimates because they are not based on CPS or other sample data.

Step 8: Control the preliminary state shrinkage estimates of the numbers of eligible infants and children to sum to the national totals for eligible infants and children obtained from the CPS. The most recent national CPS sample estimates are typically used to develop the budget for the WIC Program. To obtain final shrinkage estimates for states that sum (aside from rounding error) to the national totals from the most recent CPS (March 1993), we ratio adjust the preliminary state shrinkage estimates. This ensures that the estimates used to allocate funds are consistent with the estimates generally used to determine total program funding. The adjustments were small, with ratios of about 0.99 and 1.03 for infants and children, respectively.

Second Generation Estimates. The strengths of the shrinkage estimates obtained from our second generation estimator are that they are more timely than census estimates and substantially more precise than direct CPS estimates. As documented in Schirm (1995), the shrinkage estimates have much smaller standard errors and much narrower confidence intervals than CPS estimates. A shrinkage confidence interval is, on average, 61 percent narrower than the corresponding direct sample confidence interval. According to rough calculations, that is about the same gain in precision that would be obtained from increasing the sample size of the CPS from under 60,000 households to nearly 400,000 households--a 6.5-fold increase.

While using a shrinkage estimator greatly narrows confidence intervals and reduces our uncertainty, using shrinkage estimates makes an important difference in how WIC funds are distributed. Table 1 shows that there are several large differences in fair shares when the fair shares are calculated using shrinkage rather than census estimates. Even a small difference in fair shares can affect a state's WIC grant, however, because the funding formula contains a threshold. Specifically, a state receives growth funds only if its stability funding is below its fair share. A small increase in a state's fair share may make it eligible for growth funds, while a small decrease might make it ineligible.

FCS used the shrinkage estimates of infants and children income-eligible for WIC in 1992 to determine state WIC food grants for fiscal year 1995. Over $125 million in growth funds have been distributed.

4.3 The Third Generation Estimator

Our second generation estimator borrows strength to improve precision. However, there is more strength to be borrowed. The second generation estimator uses census estimates for the "base" year (1989) and CPS estimates for the "current" year (1992 for the most recent set of estimates). Estimates for intervening years are not used, although CPS data for obtaining such estimates are available. With each intervening year, we are ignoring more information that could be relevant. An unusually large increase in WIC eligibles over three years, for example, would be more plausible and look less like sampling error if it appeared to consist of a series of modest increases rather than two small decreases followed by one enormous jump. Using data for only the base and current years, however, the second generation estimator cannot distinguish those two patterns of change. Also, with the second generation estimator, we can do little if our regression model seems to persistently under- or overpredict for a state, short of finding a predictor variable that explains why that state is different from all the other states.

An advantage of Bayesian shrinkage methods is that they allow additional data to be used in a systematic, rather than ad hoc, way. We are currently developing a third generation estimator that is both domain and time indirect, borrowing strength across not only states, but also time. We anticipate that the state WIC eligibles estimates for 1993 will be derived from census data for 1989, as well as CPS data for 1990, 1991, 1992, and 1993. Administrative records data for all five years (1989-1993) will also be used. The third generation estimator will take account of correlations among sample estimates from different years and correlations among regression model prediction errors from different years.

5.0 CONCLUSION

Since its inception, the WIC program has undergone important changes. Over the last few years, funding for the program and the number of program participants have risen dramatically. The formula for allocating funds to the states was also revised significantly to place greater emphasis on the number of eligibles in each state as the basis for calculating state WIC grants. This new emphasis, coupled with rapid program growth, heightened the need for timely, accurate state estimates of WIC eligibles. Responding to that need, we have developed a Bayesian shrinkage estimator that optimally averages CPS sample estimates with predictions of WIC eligibles from a regression model. The predictions are based on observed changes in government program participation and other indicators of socioeconomic conditions. The shrinkage estimates obtained are more timely than census estimates, which had been used for fund allocation prior to the use of shrinkage estimates for fiscal year 1995, and substantially more precise than direct CPS estimates. The shrinkage estimator improves precision by borrowing strength, using data from all the states to derive each state's estimate. We are currently developing a new shrinkage estimator to take account of even more information and borrow strength across both space and time. Hopefully, the new estimator will provide even better estimates for allocating WIC funds to the states.

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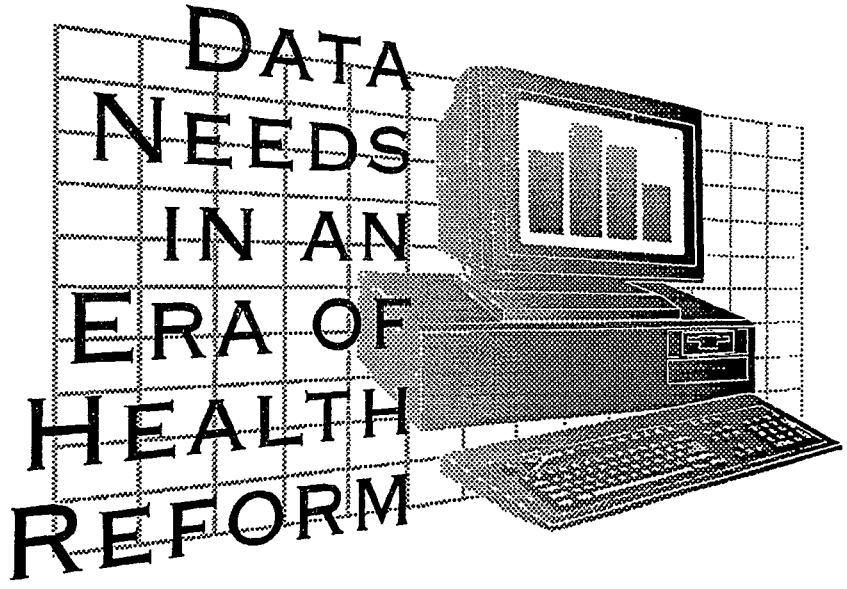
Table 1. Effect of Using Shrinkage Rather than Census Estimates

Change in Fair Share (Percentage Points)			States	
2.0	to	3.0	1	(CA)
1.0	to	2.0	0	
0.5	to	1.0	1	(FL)
0.2	to	0.5	3	(NY, NJ, MD)
0.1	to	0.2	1	(CT)
0.0	to	0.1	13	
−0.1	to	0.0	16	
−0.2	to	−0.1	11	
−0.5	to	−0.2	5	(OH, LA, PA, MI, WI)

Session C

Mental Health Issues in Ambulatory Care Settings



PATIENT CARE GUIDELINES: ANXIETY AND DEPRESSION SCREENING ISSUES IN MEASUREMENT

Lori A. Cornelius-Quast, Mayo Clinic, Mayo Foundation
Jim Naessens, Charles Darby, Jennifer Ferguson, Greg Angstman, Steve Hagedorn, Priscilla Van Grevenhof

Introduction

The 1990's were declared the "Decade of the Brain" by President Bush and Congress. We are at the midpoint of a new era in brain and behavioral sciences. Computer technology accompanied by an increase in behavioral research has produced more information about the root causes and appropriate treatment of mental illness. Within the realm of mental illness are the devastating disorders of anxiety and depression.

Anxiety disorder and depression are misunderstood and underestimated as health problems. 7-12% of men and 20-25% of women will have major depression in their lifetime according to the Agency for Health Care Policy and Research (AHCPR) Clinical Practice Guideline on Depression. The National Institute of Mental Health states that generalized anxiety disorders affect 12.6% of the people in the United States.

In 1993 the U.S. Department of Health and Human Resources Public Health Services Depression Guideline Panel estimated that the prevalence of major depression in primary care outpatients is 4.8-8.6%, while the prevalence rate for anxiety disorder is 6.5% in primary care. However, historically primary care providers have detected only one-third to one-half of patients with major depressive disorder.

Numerous reports in the literature suggest that primary care providers under-diagnose and/or under-treat depressive conditions. It was with this information in mind that priority was placed on the development of clinical practice guidelines for recognition and treatment of depression and anxiety disorders in the primary care setting.

Clinical guidelines are a consenual product developed to reflect the current state of knowledge on effective and appropriate care based on research and clinical experience. Each guideline is periodically reviewed and updated based on the continual changes in scientific information and available technology. By promoting early detection and treatment of these devastating disorders, clinical guidelines are intended to make important contributions to the health of our community, lessen the costs of health care, and contribute to the scientific understanding of these common and very disabling conditions.

Currently two guidelines addressing anxiety disorder or depression are being utilized by primary care providers. A guideline developed by the Agency for Health Care Policy and Research (AHCPR) deals specifically with detection, diagnosis, and treatment of depression in primary care. The Institute for Clinical Systems Integration (ICSI), of which Mayo is a participating member, has also developed guidelines relating to the screening and treatment for anxiety disorder and depression in primary care. The Section of Health Services Evaluation at the Mayo Clinic Rochester collaborates with ICSI in the development, implementation, and measurement of practice guidelines.

Once a guideline is fully implemented, baseline, in-process, and end-results data are collected on a pre-determined time schedule. Baseline data is collected retrospectively. It allows the medical practice to be measured prior to introduction of the guideline. In-process data allows for measurement of a practice as a guideline is introduced, reviewed, and implemented by the clinic sites. End-results data identifies any significant change in practice after implementation is completed. All data is analyzed and presented to the individual implementation sites where it can be used to explore and improve the understanding of practice patterns.

This paper presents baseline data for anxiety disorder and depression screening and diagnosis from the Mayo Clinic Rochester. Patient populations were generated from three primary care sites using ambulatory billing data. We focused on the four patient groups which according to the Institute for Clinical Systems Integration guideline are at high risk for depression or anxiety disorder (Institute for Clinical Systems Integration, 1994).

METHODS

Patients at high risk for anxiety disorder or depression include those diagnosed with irritable bowel syndrome, fatigue, sleep disorders, and patients with six or more visits to a primary care site within six months. Using electronic billing data from the period October 1994 through December 1994, a simple random sample of patients were selected by appropriate ICD-9 diagnosis codes. The selected visit must have been a new diagnosis or the first occurrence of the symptom at the identified site. These medical records were collected and reviewed by an RN to gather the data.

Symptoms present differently for anxiety and depression. Therefore the screening criteria used was specific to each diagnosis. Positive screening criteria for depression was documentation on the visit which identified any of the following statements: the patient is sad, down, blue or teary; the patient has diminished interest in usually enjoyable activities; or the patient is unable to have fun. Many variations of these statements were found as was documentation that the patient did not have these symptoms.

The positive screening criteria for anxiety disorder was more inclusive. Documentation of one of the following must have occurred on the visit identified: excessive worrying; sudden out-of-the-blue attacks of fear, terror, or apprehension; attacks of anxiety, panic, or severe embarrassment; a sense of impending doom; fear of loosing control; a fear of dying, fainting, or of going crazy; identified situations or places that are avoided; anxiety that causes significant distress or avoidant behavior in your daily life. This type of documentation was seldom present in the patient record.

In order to find the first diagnosis of the identified symptoms, we excluded any patient with a visit for the symptom of interest within the previous six months. We also excluded any patient with an anxiety disorder or depression diagnosis or a visit to a psychiatric provider in the previous six months for all four groups. In keeping with the intent of the ICSI guideline, all patients aged 18-64 identified as having irritable bowel syndrome, fatigue, or sleep disorder were sampled. Up to 30 patients per month were selected from the three primary care sites for the multiple visit criteria.

RESULTS

Overall, the data was collected on 274 patients. Of this population 22% were screened for anxiety disorder or depression, and 27% of those screened were actually diagnosed as having an anxiety disorder or depression. Of this sample, 70.8% were women. The average age of this population was 43. The demographics and screening results from each patient group are presented in Table 1.

Irritable bowel syndrome was defined by ICD-9 code 564.1 (colon, irritable). We identified 51 patients with irritable bowel syndrome among the three primary care sites during October-December 1994 who fulfilled the criteria for this guideline. The age distribution ranged from 19 to 63. Only 8% of these patients were screened for anxiety disorder or depression; and from those screened, 25% were diagnosed with anxiety disorder or depression.

Fatigue was defined using ICD-9 code 780.7 (malaise, fatigue). 13-29% of patients with a complaint of chronic fatigue may have anxiety disorder (Manu, 1991). Also fatigue is the seventh most common symptom in primary care, and up to 24% of all patients surveyed in primary care clinics indicate that fatigue is a problem (Kroenke et al, 1988). We identified 125 patients with fatigue who fulfilled the criteria for this guideline. The age distribution ranged from 18 to 63. Nearly 34% of this sample were screened for anxiety disorder or depression; and of those screened, 24% were diagnosed with anxiety disorder or depression.

The symptom of sleep disorders had several ICD-9 diagnosis codes of which we used four: 780.50, 780.52, 780.55, and 780.59. These respectively relate to unspecified sleep disturbance; insomnia not otherwise specified; disruptions of 24-hour sleep-wake cycle; and other. The ICD-9 diagnosis codes dealing with sleep apnea were not used. Twenty patients, who fulfilled the criteria for this guideline, were identified with sleep disorder. Of those identified, 55% were men. This was the only sample that contained more men than women. The age distribution was 19-50. One half of the twenty patients identified were screened for anxiety disorder or depression, and of that sample two were diagnosed with anxiety disorder or depression.

According to a study done by Weissman and Klerman, patients with undiagnosed depression average more than six visits per year with their primary care provider(Weissman and Klerman, 1977). Patients with anxiety disorder have the highest risk of having multiple medically unexplained symptoms and of being high utilizers of medical ambulatory services compared to people with and without psychiatric disorders in the community (Katon, 1992). This is a valuable population to measure for anxiety and depression screening.

To obtain the multiple visit sample we examined a moving window of six months in which six visits at any primary care site must have occurred. A patient's sixth visit defines the site at which the guideline is applied and measured. Excluded from this group were any patients with obstetric or nurse-only visits.

Table 1

	Irritable bowel syndrome	Fatigue	Sleep disorder	Multiple visits
Sample size	n = 51	n = 125	n = 20	n = 78
Age: Mean	46.7	41.9	39.4	41.9
sd	13.2	12.1	12.1	12.3
# female	82.4%	70.4%	45.0%	70.5%
# screened	7.8%	33.6%	50.0%	5.1%
# diagnosed	25.0%	23.8%	20.0%	75.0%

To eliminate nurse-only visits such as blood pressure checks, injections, or throat cultures, we included only those CPT-4 codes which indicate patient-physician interactions and excluded minor contacts. 78 patients were identified as having multiple visits who fulfilled the criteria for this guideline. The age distribution was 20 to 63. Of this sample, only 5% were screened for anxiety disorder or depression; and of that population, 75% were diagnosed.

DISCUSSION

Several similarities emerged from this data. The average age for our samples ranged from 39 to 47. Also three of the four groups had substantially more women than men ($p=.021$). The screening rate for anxiety disorder and depression was very low except for the symptoms of sleep disorder and fatigue ($p<.001$). Among those screened, the diagnosis rates were also relatively low.

Some limitations also became apparent. The sample selection was based entirely on billing diagnosis. The social stigma and ramifications of being diagnosed with anxiety disorder or depression may lead providers to under report these conditions. The method on which we relied to determine if these patients had a "new" diagnosis of the presenting symptom was no billing diagnosis in the prior six months. Therefore we may not have a representative sample of the primary care population. Also we did not have a gold standard assessment of anxiety or depression and cannot assess the sensitivity or specificity of our measures. We had no prior data to use as a comparison.

Identifying true multiple physician visits was difficult within our system. This population was easy to define but difficult to operationalize. Our original multiple visit sample included patients seen only by a nurse for blood pressure checks, immunizations, and throat cultures. Patients were also identified because of multiple telephone consultations. After some initial chart review we used only selected CPT-4 codes to ensure 6 provider visits in primary care within the 6 month window. We do not know if this is a limitation to our system or to the medical billing system at large.

CONCLUSION

In conclusion, measuring the screening and diagnosis rates of anxiety disorder and depression in primary care in these sub-populations is a worthwhile activity. This activity assesses which providers are utilizing practice guidelines for screening and diagnosing these mental health conditions. In our current practice, fatigue and sleep disorders are more readily identified by primary care providers as being risk factors for anxiety disorder and depression. The overall screening and diagnosis rates for anxiety disorder and depression in these populations identify areas for quality improvement among primary care providers.

In this era of health care reform the quality and cost of medical care are major focal points. Health statistics such as anxiety disorder and depression screening rates indicate that resources should be directed to the recognition and treatment of anxiety disorder and depression in primary care. These statistics can also be used to generate interest in some of the current and future public health needs identified by the National Institute for Mental Health, such as the prevention of mental illness and promotion of mental health in the primary care setting.

As the process of developing clinical practice guidelines evolves, we can examine how different aspects of the entire care process such as diagnosis, treatment, and management fit together. This information can be used as building blocks for science-based performance measurement and standard setting in health care.

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AN HMOs FIRST YEAR OF EXPERIENCE WITH THE HEDIS 2.0 MEASURE: AMBULATORY FOLLOW UP AFTER HOSPITALIZATION FOR MAJOR AFFECTIVE DISORDER

Lora Means, Blue Cross and Blue Shield of the Rochester Area
Kathyrn Cleary

Continuity of care following hospitalization has been a long-standing concern in the mental health field. Of most concern is that symptoms of depression frequently are not recognized by practitioners and only 31% of people with major affective disorders receive treatment of any kind (Public Health Service, 1990). The Health Plan Employer Data and Information Set (HEDIS 2.0) has drawn attention to this concern by establishing a quality indicator measuring whether a patient was seen in an ambulatory setting within 30 days post major affective disorder discharge. In an effort to report this and other HEDIS 2.0 measures in 1994, Blue Choice, an Individual Practice Association (IPA) model HMO, located in Rochester, New York with more than 410,000 members undertook a three phase analysis of follow-up care rendered to patients discharged with the diagnosis of major affective disorder. Phase I measured compliance with the HEDIS 2.0 specifications. Phase II measured compliance with the NCQA Report Card Pilot Project specifications. Phase III consisted of reviewing administrative records of patients not meeting the Phase II specifications for follow-up. The Phase I specification yielded 250 major affective disorder discharges in 1993 (31% of all mental health discharges). The 30 day follow-up rate was 70.4 %. The phase II criteria increased the 30 day follow-up rate to 86.3%, with a denominator of 204 discharges. This left 28 patients whose discharge aftercare was undetermined. Phase III demonstrated that out of the 28 members, 20 members had been followed up within 30 days, but in a health care setting unrecognized by the HEDIS or NCQA Report Card Pilot Project criteria. The types of follow-up care rendered are summarized and discussed. These findings will stimulate further discussion of how to measure quality of care provided to this vulnerable population.

Introduction

Major affective disorders, particularly depression, are among the most frequently occurring psychiatric disorders. Up to 5% of U.S. adults, or about 11 million people, may suffer from depression at any one time.[1] According to a new study by a team of economists at the Massachusetts Institute of Technology, depression costs the U.S. $43.7 billion per year in worker absenteeism, lost productivity, and health care.[2] Depression tends to be more debilitating than diabetes, arthritis, gastrointestinal disorders, back problems, and hypertension in terms of physical functioning; interference in work, housework, or schoolwork; and normal social functioning.[3] As a consequence, the Public Health Service, in its Healthy People 2000 document, has established a goal to increase to at least 45% the proportion of people with major depression disorders who receive treatment.

One concern regarding inpatient treatment is the need for improved continuity of care. Consistently, aftercare services have been shown to improve the quality of life and reduce the clinical symptoms of psychiatric inpatients. Studies suggest that recently discharged inpatients who receive some kind of aftercare (e.g., medications, psychotherapy, occupational therapy, or case management) will function better after leaving the hospital than those who do not.[4] However, although there is widespread recognition of the need for providing transitional care services, there is also wide variability in the extent to which providers have been willing to take responsibility for, and intensively implement, measures to ensure effective aftercare.[4] This is one reason why ambulatory follow-up after hospitalization for major affective disorder is a key process measure in the Health Plan Employer Data and Information Set (HEDIS 2.0). This paper will describe an HMO's first year experience with the HEDIS 2.0 Ambulatory Follow-Up after Hospitalization for Major Affective Disorder measure, as well as the opportunities for improvement that were identified both in clinical practice and in the HEDIS 2.0 measure specifications.

This study encompasses three phases. The first phase describes our 1993 results using the HEDIS 2.0 specifications for the Ambulatory Follow-Up after Hospitalization for Major Affective Disorder measure. Phase two describes our results using the National Committee for Quality Assures (NCQA) Report Card Pilot Project specifications for the same measure, and phase three reviews what happened, and illustrates ways in which we can improve care provided to our members.

Local Environment

In Rochester, N.Y., HMOs enroll 54% of the insured population, the highest penetration of managed care in any metropolitan area in the United States. Rochester is unique in that it has a long history of effective regional health planning and capacity control. Hospital occupancy rates in the Rochester area average about 88%, compared with a national average of

68%. In Rochester, instead of focusing on competition with each other, local hospitals work together to coordinate and share their services to avoid unneeded duplication.

Blue Choice is an IPA-model HMO established in 1985, and operates as a line of business of Blue Cross and Blue Shield of the Rochester (New York) Area. With over 410,000 members in 1993, Blue Choice is the second largest IPA-model HMO in the United States.

Blue Choice's mental health benefit structure provides full coverage for 30 days of inpatient hospitalization, and up to 20 outpatient visits with a 50% copayment. The mental health panel consists of psychiatrists, psychologists, and certified social workers. Services rendered by non-participating providers are not covered, they are denied. Blue Choice also has a Psychiatric Case Management Program, Personalized Benefit Services (PBS), designed to meet the needs of members who are mentally ill or chemically dependent. The goals of this program are to provide access and appropriate treatment alternatives to members while maintaining high quality, cost-effective care. PBS case managers spot opportunities for alternative care that may be more appropriate, more comfortable for the patient and less expensive. For example, PBS case managers will use what is remaining in the mental health inpatient benefit to "buy" ambulatory care visits, and can sometimes utilize the chemical dependency detoxification benefit. PBS case managers have also paid for travel expenses to get patients to and from health care appointments.

Phase I Methods

In Phase I, the HEDIS 2.0 specifications were used for calculating the ambulatory follow-up after hospitalization for major affective disorder rate. All hospital admissions for adult members ages 18-64 with a primary discharge diagnosis of major affective disorder (i.e., ICD-9 code of 296.xx) were identified.

The rate was then calculated based on the patients in the target population who received a follow-up visit from a mental health provider within 30 days after their discharge. The follow up visit must have been coded with a major affective disorder diagnosis. The ambulatory follow-up visit was identified using the HEDIS 2.0 specified CPT-4 and revenue codes as well as local codes used in conjunction with the major affective disorder ICD-9 diagnoses codes (296.xx).

CPT-4 Codes	90801, 90841, 90843, 90844 & 90844.22, 90847 & 90847.22, 90849,90853, 90862, 90870, 90871, 98900,and 98902
Revenue Codes	900, 912, 913, 914, 915, 916, 918, and 919
Day Hospital Local Codes	X9081, X9082, X9083, and X9084

Phase I Findings

There were 250 major affective disorder discharges in 1993 (31% of all mental health discharges). Of these discharges, 176, or 70.4%, had received ambulatory follow-up care within 30 days of discharge (74 patients had no follow-up care).

Phase II Methods

In Phase II, the NCQA Report Card Pilot Project specifications were used for measuring the ambulatory follow-up after hospitalization for major affective disorders. The target population was persons who were 18-64 years of age at the time of discharge, who had been hospitalized with a discharge date occurring during the first 330 days of the reporting period, had a principal ICD-9 diagnosis code indicating a major affective disorder diagnosis (296.xx), and *were continuously enrolled for 30 days* after admission.

The ambulatory follow-up visit was identified using only the HEDIS 2.0 specified CPT-4 codes, revenue codes and our Plans' local codes (described in the Phase I Methods). The rate was then calculated based upon the discharges for the target population who received a follow-up visit with a mental health provider within 30 days, with *no limitation on the mental health diagnosis* for this visit.

Phase II Findings

Again using the same patient base as in Phase I, there were 204 major affective disorder patients in 1993 who met the age criteria of 18-64 years of age and were continuously enrolled for 30 days after admission. (Please note that Phase I (HEDIS 2.0) did not include continuous enrollment criteria, and therefore the denominator has changed from 250 in Phase I to 204 in Phase II.) Of the 204 major affective disorder patients, 176, or 86.3%, had received ambulatory follow-up care within 30 days of discharge. This left 28 members whose aftercare was undetermined.

The table below illustrates the differences between Phase I (HEDIS 2.0) and Phase II (NCQA Pilot Project) results.

	# of Discharges	Ambulatory Follow-Up	Undetermined aftercare
HEDIS 2.0	250	176	74
NCQA Pilot Project	204	176	28

Of the 176 patients that received follow-up care, 152 or 86% were the same patients in Phase I as in Phase II. The 24 patients left were either not included in Phase I due to the limitation on diagnosis code for the follow-up visit, or were not included in Phase II because of the continuous enrollment criteria.

Phase III Methods

Phase III research consisted of reviewing each of the remaining 28 members' claims history online. This was a preliminary step in an effort to set up a process for ensuring follow-up within 30 days for future major affective disorder discharges.

Phase III Findings

The outcome of this research demonstrated that 20 of the 28 patients had been followed up within 30 days, but in a health care setting not specified by the HEDIS or NCQA Report Card Pilot Project criteria.

The following table summarizes the way in which these 20 patients received follow-up care:

Reasons for Exclusion	Number of Patients
Followed up by a non-mental health provider - Primary Care Physician - Chemical Dependency Provider	7
Followed up by a mental health provider but were not included because the claims were denied	3
Followed up but were not included due to local coding and specification issues	10

This left 8 patients who did not receive follow-up care within 30 days of discharge. The following table illustrates what happened to those eight patients who did not receive follow-up care within 30 days.

Reasons for Exclusion	Number of Patients
Received follow-up care after 30 days	3
Left hospital against medical advice and no subsequent follow-up	1
No additional mental health utilization	4

Discussion

It has been demonstrated that seeking health care within 30 days of discharge, for reasons other than the diagnosis for which they were admitted, directly correlates to the prevention of post-discharge reactions. Therefore, ambulatory follow-up visits that are not diagnosis driven are similarly beneficial in preventing re-hospitalization.[5] The NCQA Report Care Pilot Project specifications did improve our plan's measure of quality due to the relaxed specifications on mental health diagnosis, and to the addition of the continuous enrollment criteria. Using these specifications, our plan's rate increased 23%, from 70.4% to 86.3%.

The results from Phase II indicated that we did have some missed codes in which patients should have been in our follow-up sample (i.e., local code X919, and individual case management). We also had an opportunity to increase our follow-up rate by using our denied claims file, as our analysis revealed 3 patients who did receive follow-up care but whose claims were denied. Once these gaps are closed, we will feel more comfortable that the HEDIS specifications represent a true picture of the quality of care provided.

Interventions

To achieve a higher ambulatory follow-up rate and to improve mental health outcomes, four interventions are being developed and implemented.

1. When a mental health patient has been discharged from an inpatient setting, our referral system will automatically generate a reminder letter to the patient about their first follow-up visit.
2. Personalized Benefit Services case managers will begin to actively participate in discharge planning with providers. For example, the case managers will make sure that the patient is receiving follow-up care with a participating provider, so that the patients will receive the proper reimbursement. As stated previously, Blue Choice will not reimburse for visits to a non-participating provider.
3. Personalized Benefit Services case managers will also make sure that the patient's follow-up visit is occurring within a reasonable amount of time through the discharge planning phase.
4. Through the discharge plan, Personalized Benefit Services' case managers will actively identify potential case management patients.

Recommendations

After thorough analysis of the 28 members who did not meet the HEDIS 2.0 or NCQA Report Card Pilot Project criteria for follow-up care, a recommendation was made to NCQA regarding an improvement to the Ambulatory Follow-Up after Hospitalization for Major Affective Disorder specifications.

1. Allow visits to chemical dependency providers to count as follow-up care. Blue Choice, like many other HMOs, has a growing mentally ill/chemical abuser (MICA) population in which the patient is served by both systems. For instance, a MICA patient will be admitted to a mental health inpatient facility to treat his/her mental illness and when discharged, that patient will then receive an ambulatory follow-up visit with a chemical dependency provider to receive care for their chemical dependency.

This is an HMO's first effort at measuring and improving the Ambulatory Follow-Up After Hospitalization for Major Affective Disorder rate. Valuable interventions have resulted from this research, and we look forward to continuing to improve the quality of health care services.

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THE DELIBERATE MISDIAGNOSIS OF MAJOR DEPRESSION IN PRIMARY CARE

Carla D. Williams, University of Arkansas for Medical Sciences
Kathryn Rost

Introduction

Major depression is a prevalent problem in primary care settings. Studies estimate that 5% - 10% of primary care patients suffer from depressive illness.[1] The literature suggests that as many as 50% of patients with depressive symptoms do not have the condition diagnosed by their primary care physician.[2,3] However, estimates taken from existing clinical databases may inaccurately characterize the incidence of depression and the process of treatment in the primary care setting. In many cases, patients' psychiatric symptoms are recognized and sometimes pharmacologically treated, however, a psychiatric diagnosis is not noted in the patient's record.[4]

The current diagnostic coding system provides physicians with an array of codes that can be substituted for depression. Doctors often deliberately miscode depressive illness to avoid many of the negative consequences of making a psychiatric diagnosis.[5] For primary care physicians, a major consequence of diagnosing and treating depression is being subjected to lower rates of reimbursement by third-party payers.[6] Tolerating inequitable reimbursement policies is an undesirable outcome for providing appropriate care and may provide an incentive for using alternative diagnostic codes.[7]

It is important to note, however, that many of the reasons for alternative coding are not related to unacceptable outcomes for physicians, but rather to the negative impact of subsequent stigmatization of patients who receive a psychiatric diagnosis. Many physicians are aware that a psychiatric diagnosis can delay recovery and jeopardize a patient's future ability to obtain life and health insurance, to secure disability benefits, and to gain employment. Physicians are therefore cautious in making a diagnosis of depression for fear of harmful repercussions for their patients.

Although primary care physicians may seem to have justifiable reasons for deliberately miscoding major depression, the practice of deliberate misdiagnosis invalidates the use of existing databases in determining the actual role of primary care physicians in the provision of mental health treatment. Under current health care policy, insurance coverage and reimbursement rates for psychiatric disorders are often subject to more limitations than coverage and reimbursement for physical health problems.[8] The decisions which allow such inequities to continue are based, in part, upon inaccurate data which indicate psychiatric disorders are infrequently or ineffectively treated in primary care settings.

To address problems with utilizing current clinical databases to characterize the delivery of mental health services in primary care settings, a study was undertaken to estimate the prevalence of alternative coding of depression in primary care and to identify the reasons for its occurrence.

Methodology

Primary care physicians from practices across the U.S. were randomly selected from the membership directories of the American Academy of Family Physicians and the American College of Physicians. Equal numbers of physicians from each professional group were selected to yield a total sample of 634 physicians.

A one-page questionnaire was mailed to each participant. After two weeks, a second survey was mailed to physicians who had not responded. Physicians who did not respond to either mail survey were contacted by telephone 3 - 5 weeks after the initial mailing. To maximize the response rate, extensive socio-demographic data and information about practice characteristics were not collected from individual physicians. The professional organizations that supplied physician names and addresses identified physician specialty. Information about the demographic characteristics of the county in which the physician practiced was obtained from the 1990 U.S. Census.

The survey asked respondents to estimate the number of adult outpatients they had seen in the preceding two weeks and to estimate how many of those patients met DSM-III-R criteria for major depression at the time of the visit. (A one-page guideline for diagnosing major depression was included on the reverse side of the questionnaire.)

Physicians were asked if they used an alternative diagnostic code for major depression with any of their patients. If so, they were asked to estimate how many of those patients received an alternative code. Doctors who reported deliberately miscoding major depression were given a list of nine possible alternate codes and asked to identify the three codes most commonly substituted. Additionally, participants were given nine reasons for deliberate miscoding and were asked to list the three most compelling reasons for using alternative codes.

When physicians were given multiple response options, an "other" category was included. Those who selected "other" were asked to specify an alternate response. The content of those responses was analyzed and, where appropriate, incorporated into closely related existing categories. Two new response categories for reasons for miscoding were developed as a result of the content analysis.

Results

Surveys were completed for 70% (N = 444) of participants. Sixty-four percent of completed surveys were returned by mail and 36% were completed by telephone interview. Twenty-two percent (N = 138) of physicians sampled could not be located by mail or telephone and 8% (N = 52) refused to participate.

Physicians estimated that 6.6% of patients seen during the preceding two week period met DSM-III-R criteria for major depression. Analysis of responses revealed that 50.3% of physicians (N = 192, SE, ±2.5%) reported using an alternative code for at least one patient with major depression during the past two weeks. Of patients judged to meet DSM-III-R criteria for major depression, 31% received an alternate diagnostic code.

Table 1 presents the proportion of physicians who reported using each of the nine possible alternative diagnostic codes. Fatigue/malaise, insomnia, and headache were the three most frequently substituted codes.

Table 1.

Diagnoses Most Frequently Substituted*	% of Physicians Using Diagnosis
Fatigue/malaise	59.8
Insomnia	43.9
Headache	28.0
Anxiety	25.9
Adjustment/grief reaction	23.3
Other	20.1
Fibromyalgia	19.0
Anorexia	14.8
Premenstrual syndrome	4.8
Irritable bowel syndrome	4.2

* Respondents could check up to three diagnoses.

Uncertainty about the diagnosis was the reason most frequently cited for alternative coding of major depression. Difficulty with reimbursement for depression treatment was the second most common reason for substitution. Table 2 lists the proportion of respondents citing each reason for alternative coding. As a result of the content analysis of responses written in by physicians, two additional categories were identified: Patient's resistance to the diagnosis and physician's preference toward selecting diagnostic codes that reflect specific symptoms.

Table 2.

Most Frequently Cited Reasons for Substitution	% of Respondents Citing the Reason
Uncertainty about the diagnosis	46.0
Problems with reimbursement for services if depression is coded	44.4
Jeopardize future ability to obtain health insurance	29.4
Stigma associated with depression will delay patient's recovery	20.9
Jeopardize future ability to obtain life insurance	12.8
Stigma associated with depression will negatively influence future care from other providers	12.3
Patient unwilling to accept diagnosis	11.8
Explicit request from patient	11.2
Jeopardize future employment	10.2
Other	8.6
Jeopardize future ability to obtain disability	6.4
Prefer codes that reflect specific symptoms of presenting complaint	6.4

Internists were more likely to report using alternative codes, 56.1% (96/171) than family physicians, 45.5% (96/211) ($\chi^2 = 4.28$, $p = .04$). Physicians who reported using alternative codes for major depression estimated seeing 10.4 depressed patients during the preceding two week period while physicians who reported they did not use alternative codes estimated seeing 6.0 depressed patients ($t = 5.19$, $p = .0001$). The volume of patients seen in the practice did not predict use of alternative codes.

The following demographic characteristics for the counties where physicians practiced were examined: the proportion of the population age 25 and over with a high school education; the proportion of the population age 65 and over; the proportion of ethnic minorities; and median family income. Physicians' use of alternative codes did not differ based on any of the aforementioned characteristics of county of practice location.

Discussion

Results of the study demonstrate that deliberate misdiagnosis of major depression is a common practice among primary care physicians. Half of all physicians surveyed reported using alternative diagnostic codes for major depression. One third of primary care patients with major depression received an alternate code. These findings indicate that current clinical databases may grossly underestimate the prevalence of major depression in the primary care setting. Moreover, the practice of deliberate misdiagnosis precludes any realistic estimation of the primary care physician's role in the diagnosis and treatment of major depression.

The reason most frequently cited for using alternative codes was the physician's uncertainty about the diagnosis. Forty-six percent of respondents said diagnostic uncertainty was a compelling reason for alternative coding. This indicates that in order to more accurately characterize the treatment of depressive disorders in primary care, it will be necessary to increase physicians' confidence in making the diagnosis.

Physicians obviously recognize a substantial number of their patients who meet criteria for major depression. However, doctors often lack confidence in their ability to adequately treat patients with major depression while avoiding many of the negative consequences associated with being diagnosed with a depressive illness. Providing guidelines for the diagnosis and treatment of psychiatric disorders in primary care may reduce some of the diagnostic uncertainty and thereby alleviate the reticence physicians exhibit in treating their depressed patients.

Future Data Needs

Data obtained from detailed reviews of written medical records could provide important insight into physician recognition of depression and the consequent treatment decisions. Systematic reviews of physicians' notations could potentially reveal awareness of patients' depression in the face of diagnostic uncertainty. Comparisons of physicians' detailed patient notes to the diagnostic codes actually recorded would identify instances where depression was a potential diagnosis, but alternative codes were recorded.

Likewise, creating and maintaining computer databases that contain patients' complete problem lists could be beneficial in identifying patients with depressive symptomatology. The utility of computer-assisted diagnostic coding based on patient

problem lists is already being explored.[9] It is reasonable to believe that the recording of psychiatric disorders presenting to the primary care setting could be improved through the use of computer-aided coding technology.

Additionally, enhancing interdisciplinary treatment networks could serve to bolster primary care physicians' willingness to address mental health problems with their patients. Availability of consultation and referral services would provide networks of support for physicians who encounter difficulties in treating depressed patients. Maintaining data on formal and informal physician referrals to specialty mental health care would provide another indicator of the recognition of depression and other psychiatric disorders in the primary care setting.

Conclusions

While it is important to address physicians' concerns about adequately treating depressed patients in the primary care setting, the crux of the problem of deliberate misdiagnosis lies with the second most common reason physicians gave for deliberately misdiagnosing major depression. Forty-four percent of physicians noted problems with reimbursement for treating psychiatric disorders as a compelling reason for employing deliberate miscoding.

This study reveals that deliberately miscoding major depression is a tactic widely used by physicians to circumvent the negative consequences of treating mental health problems in the primary care setting. Physicians' decisions to employ deception to avoid the restrictions third party payers place upon reimbursement for mental health treatment serves only to perpetuate the inequitable policies now in existence. Allowing insurers to continue to enforce discriminatory policies does a great disservice to both doctor and patient.

Inequitable coverage for mental health problems is based upon the idea that treatment for mental health problems is less beneficial than treatment for medical conditions. There is a preponderance of evidence to support the contrary. Many effective treatments for major depression are now available.[10] Physicians have a responsibility to challenge these ill-founded policies by correctly identifying and treating depressed patients in the primary care setting and reporting the actual process and outcomes of that treatment. Analysis of clinical databases would then provide clear evidence of the primary care physician's role in treating depressive disorders. As the actual rates of treatment of depression in primary care become apparent and the good outcomes of those treatments are demonstrated, insurers would be forced to re-examine the policies that potentially limit a patient's ability to receive appropriate treatment in a low cost setting such as primary care.

In the mean time, it is necessary to collect primary data which accurately describes the prevalence of depressive illness among primary care patients. This can be accomplished by utilizing one of several screening tools normed on primary care populations.[11,12] Additionally, it is necessary to collect and disseminate information about the outcomes of treatment for depression received from the primary care sector. An Outcomes Management System has been developed explicitly for the purpose of monitoring the outcomes of depression treatment.[13] Data collection and dissemination by researchers will support the primary care physician's efforts to dispel the myths about depression among primary care patients. In partnership with researchers, primary care physicians can effectively demonstrate the frequency with which depressed patients seek treatment from primary care providers and can allow for fact-based comparisons of treatment outcomes in primary and specialty care settings.

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DEVELOPING AND TESTING DATA COLLECTION INSTRUMENTS TO CHARACTERIZE PSYCHIATRIC PATIENTS AND CLINICAL PRACTICE PATTERNS

Joyce C. West, American Psychiatric Association

Purpose: The APA is developing a Practice Research Network (PRN) to conduct clinical and services research. An initial objective is to develop core instruments to systematically characterize Network members, their patients, and clinical practice patterns.

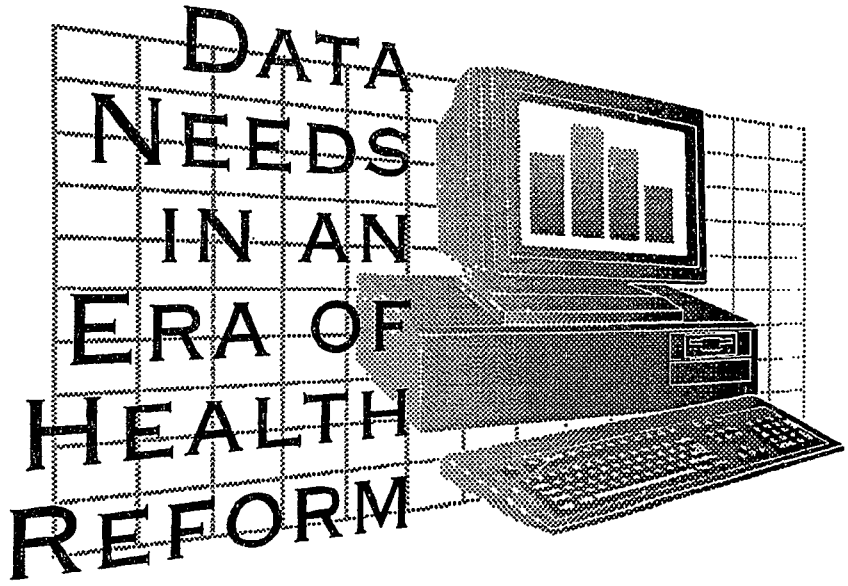
Methods: The core Network member instrument collects data on Network members' demographics, training, and practices. The core patient-level instrument collects data on: patient sociodemographics; treatment setting/ plan; diagnostic information (all DSM-IV axes); and mental health treatments. One hundred seventy-six APA members practicing in the full range of inpatient and outpatient treatment settings volunteered to participate in the Network and test these instruments. The instruments and protocols were mailed. Reminder postcards, telephone and fax reminders were administered.

Findings: Ninety percent of the 178 Network members completed the Network member survey; 95% of the 158 members who responded to the survey completed the patient-level instrument on five systematically selected patients, providing data on 300 patients. Quality of the data appears good based on the low missing data rate and initial validation. Data on the sociodemographic characteristics and practice settings of Network members compared to psychiatrists sampled in other national data bases will be presented. The majority of patients had psychiatric comorbidities: 57% had one or more Axis I mental disorders in addition to the principal disorder; 21% had two or more. Thirty-nine percent had one or more Axis II personality disorders in addition to the principal disorder; 41% had one or more Axis III general medical disorders. The most common treatments were psychiatric/medical management (65%), individual psychotherapy (53%), and medication prescriptions/monitoring (51%). Ninety percent of the patients received at least one psychotropic medication; the most common agent, fluoxetine, was prescribed for 22% of the patients. A significant proportion of patients received mental health treatments from other providers; for example, 24% of outpatients received individual psychotherapy from another provider.

Conclusions: These pilot studies demonstrate the feasibility of the PRN in collecting detailed patient-level data from large numbers of psychiatrists. Outstanding methodologic issues, including sampling and analytic plans and instrument validation, will be discussed. Plans are underway to expand the Network and conduct a variety of studies, including longitudinal clinical effectiveness studies.

Session D

Childhood Immunizations



ASSESSING PEDIATRIC IMMUNIZATION STATUS WITHIN A PRIMARY CARE PRACTICE

Mary E. Murphy, Mayo Clinic, Mayo Foundation
James M. Naessens, Jill M. Killian, Gregory L. Angstman, Steven D. Hagedorn

Introduction

The President's Childhood Immunization Initiative establishes a national priority for the immunization of preschool children. It sets the goal of achieving immunization levels of 90% for the routinely recommended childhood vaccines in two-year-old children in this country by the year 2000. Immunizations are a cost-effective way to prevent childhood diseases and assure a healthy pediatric population[1]. By preventing illness, immunizations save lives, prevent suffering, and reduce medical costs[2]. Clearly, efforts should be made to maximize the number of children immunized.

A unified schedule for childhood immunizations was disseminated for use in January 1995[3]. In accordance with the schedule, the majority of primary immunizations should be received by age two. However, many children do not receive their immunizations as scheduled. Because of this statistic, the responsibility for achieving high immunizations rates must be shared by many people including parents, health care providers, and public health agencies[4].

In 1993, the Minnesota Department of Health estimated that only 61.4% of the state's two-year-olds had completed the basic primary series on schedule[5]. There is currently no centralized system to monitor childhood immunization status. The only way to gather this information was to do a retrospective review of the records of children enrolled in kindergarten and record the number of immunizations listed as received by age two.

Mayo Clinic, Rochester Minnesota, provides primary care for individuals and families in the surrounding geographical area. At Mayo Clinic Rochester, primary care for children is provided by two Departments: Community Pediatrics and the Rochester Family Practice Clinic. Pediatric patients can also receive medical care at an Urgent Care Center (UCC). The Kasson Mayo Family Practice Clinic is located 15 miles west of Rochester in Kasson Minnesota. This clinic provides primary care within a rural setting.

The Mayo Clinic and other health care organizations from the Midwest have collaboratively joined to address Continuous Quality Improvement in healthcare. These organizations develop clinical practice guidelines to assist the clinician in the delivery of high quality, clinically appropriate, cost-effective health care to all segments of the population in accordance with economically-efficient practices based on the principles of continuous improvement[6]. Each guideline focuses on a very specific aspect of health care, such as Pediatric Immunizations and each includes measurement specifications. The measurement results are reported back to the individual medical groups to serve as a basis for Continuous Quality Improvement. Each group can view its progress in reducing variation and producing better outcomes.

A Pediatric Immunization Health Care Guideline was implemented at Mayo in 1994. The results of the assessment performed to determine adequacy of pediatric immunization rates for 1994 are presented in this paper.

Methods

The population under study consisted of children seen in each of the two family practice clinics, the Community Pediatrics practice or the Urgent Care Center during 1994. Patients were identified through our ambulatory services billing system. Children were included if between the ages of two and two and one-half-years-old at the time of their visit. The purpose of the visit could have been for either acute or maintenance health care. Random samples of 10 patients per month per site were selected for a total sample of 480 patients. Medical records were then reviewed to determine immunization status by the child's second birthday for diphtheria, pertussis, tetanus (DPT); polio; measles, mumps, rubella (MMR); and Haemophilus influenzae type b (HIB). Hepatitis B immunization is currently not required for school or daycare attendance in MN., so data regarding it is not included. Within the guideline, there is a schedule for administration of Hepatitis B vaccine either during infancy or during adolescence. Well-child care received within the Mayo System was also recorded.

Credit was only given for an immunization in which the date (month/year) was recorded in the child's record. The immunization could have been given within the Mayo System or elsewhere. Documentation of immunizations being "up to date" was not considered sufficient. The number of immunizations required to be considered complete by age 2 are presented in Table 1.

Table 1. Required Immunizations

4	Diphtheria, Pertussis, Tetanus (DPT)
3	Polio (oral or inactivated)
1	Measles, mumps, rubella (MMR)
4	Haemophilus influenza type b (Hib)

Due to the sampling scheme, overall immunization rates were weighted by the number of children seen at each site. Statistical comparisons between sites were based on Chi-square analysis.

Results

The overall immunization rate by age two for all four sites in 1994 was 84%. This immunization rate is not population-based, but reflects the rate among two to two and one-half-year-olds brought to one of the four sites. The overall rate has been adjusted to reflect the population seen at each site, since fewer two-year-olds are seen at the Kasson Family Practice site than at Community Pediatrics. The completeness rate for each of the four sites is presented in Table 2.

Table 2. Completeness Rate by Site

Site	%
Community Pediatrics	91
Family Medicine Rochester	87
Urgent Care Center	83
Rural Family Medicine	48

Two findings were unexpected: the completeness rate for the Kasson Family Practice site is significantly lower than the Rochester-based sites ($p<0.001$), and the rate at the UCC was higher than anticipated.

Since the immunization rate at the Kasson Family Practice site was 39% lower than the average rates for the other three sites, potential underlying reasons were investigated. The rate by type of immunization comparing the Kasson practice to the overall completeness rate for all 4 sites is presented in Table 3. With the exception of MMR, which is only given once, the other three rates were similar at Kasson.

Table 3. Completeness Rate by Type of Immunization

	All 4 sites	Rural Family Medicine
DPT	86	52
Polio	88	57
MMR	94	70
Hib	91	57

Next, it was determined whether the children seen at the Kasson Family Practice lacked documentation of any immunizations being given, or if the primary series had been started, but not completed. 44% of the children had not completed all three series. On average for the three series, 19% of the children had no documentation in their medical record regarding their immunizations and 22% had missed one dose of the series (Figure 1).

The type of health care visit history for these children was examined. 97% of the children had well-child care visits at the three Rochester based sites. Only 75% of the children had well-child care visits at the Kasson Family Practice; 25% of children under age two were seen for acute care only (Figure 2).

Immunization rates were affected by more than well-child care rates alone. As shown in Figure 3, children who received well-child care at the Rochester-based sites had an immunization rate of 87%, while the rate at the Rural Family Practice site was 61%. The immunization rates for children who only had acute care visits were similarly low at all sites.

The immunization rate at the UCC was 83%. 96% of the two-year-olds seen at the UCC during 1994 had received well-child care within the Mayo System either at Community Pediatrics or at Family Medicine. The high utilization of the UCC by children ages two to two and a half who also received well-child care within Mayo and low utilization by the Rochester community at large led to the unexpected high immunization rate in the UCC.

Discussion

The process of implementing the Pediatric Immunization Guideline differed between the Rochester-based sites and the Kasson Family Practice Clinic. As part of the implementation process at both Community Pediatrics and Rochester Family Practice, steps were taken to assure high immunization rates. They chose to identify those preschoolers who did not have documented evidence that they have completed their primary series of immunizations and to either immunize them or document immunizations received elsewhere.

As an appointment is made for a child between the ages of 15 months and 5 years of age at the Rochester Family Practice Clinic or Community Pediatrics Practice, there is a verbal reminder to bring their immunization card to that appointment. A nurse or physician then checks their card against their record to assess completeness of immunizations. This is done regardless of type of appointment. If the primary series of immunizations is complete, the record is stamped with a red stamp that says 'Immunizations Complete by Age 2.' If not complete, the necessary immunization is given that day or a follow-up appointment is made.

Medical records are also screened for immunization status when being used for reasons that do not involve a patient visit, such as for dictation. If there is evidence that immunizations are complete, the record is stamped complete. If not complete, a letter is sent to the child's home stating that the medical record indicates that the child's immunizations are delayed. They are requested to call with the dates if immunizations were received elsewhere or to make an appointment

to get the necessary immunizations. If there is no response to the letter within two weeks, one reminder phone call is made.

The Kasson Family Practice did not have such a process in place in 1994. In addition, fewer of the children seen at the Kasson Family Practice site were receiving routine well-child care. Without a source of regular care, children have little opportunity to receive the full schedule of vaccines, much less on time. A child stands a far better chance of being fully immunized if he or she has one primary care provider who is likely to monitor the child's immunization status on a regular basis and to provide the required immunizations on site when these needs are identified[7].

As part of the Continuous Quality Improvement Process, the results were presented to the Kasson Family Medicine providers. They have reviewed the process they use when seeing young children and plan to apply some of the steps utilized by the Rochester-based groups. Since then, their first quarter 1995 immunization data has been reviewed and the trend is positive. Their overall completion rate increased from 48% in 1994 to 63%. A medical record review will be continued on a quarterly basis, so as to continue to provide feedback to all the medical groups.

Conclusions

- Immunization rates at Rochester-based sites were higher than those at the Rural Family Practice.
- Children who only receive acute care have lower immunization rates than those receiving well-child care.
- In addition, an opportunity for improvement in immunization rates exists among children who receive well-child care at Rural Family Practice.
- Different implementation processes were used at various sites.
- There is a need to utilize the acute care visit to review immunization status.

Each health care encounter is an opportunity to immunize. The practitioner should use every visit to check immunization records, give needed vaccines, educate parents about immunization, and schedule the next immunization appointment.

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Figure 1: Rural Family Medicine Performance for DPT, Polio, HIB

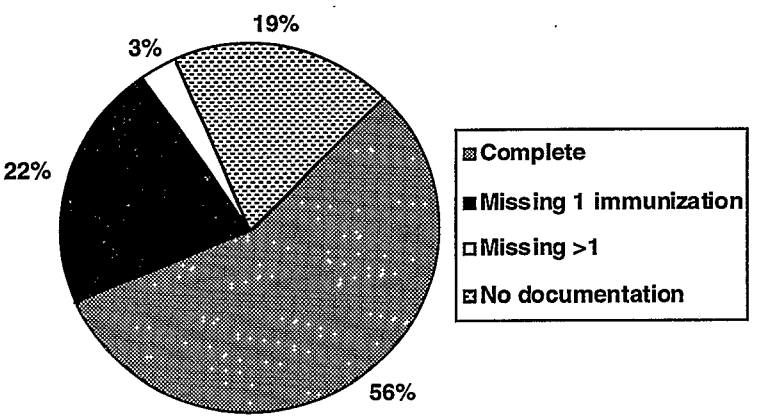


Figure 2: Well-Child Care

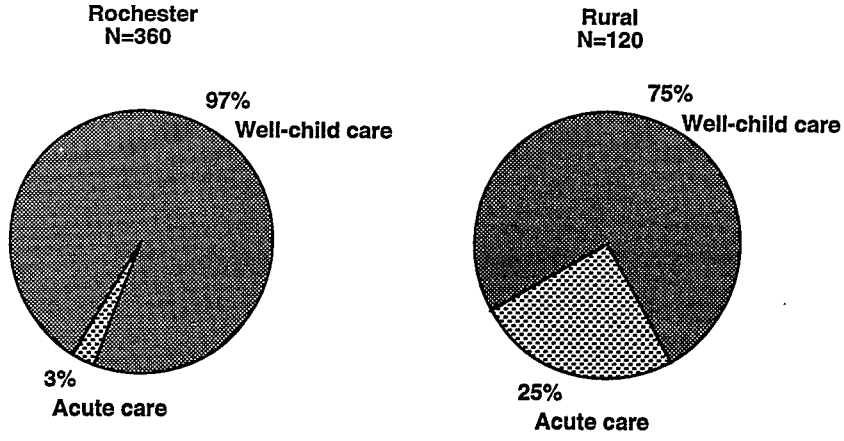
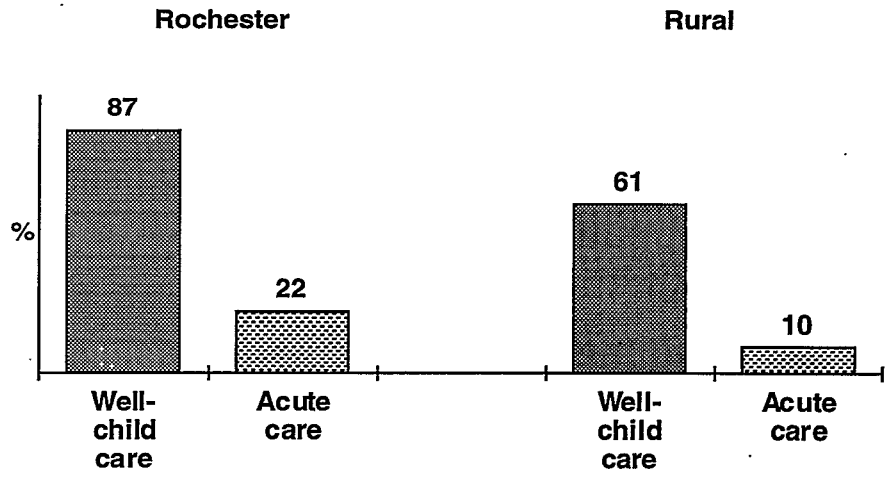


Figure 3: Immunization Rate by Type of Care



IMMUNIZATION RATES FOR A HOUSTON HMO

Dorothy McCraw Syblik, NYLCare/Sanus Healthplan

INTRODUCTION

A Health Maintenance Organization (HMO) in Houston, Texas conducted a mail survey of parents of children who were one year old in 1993. A child was classified as immunized if he/she had 3 DTPs, 2 OPVs, and 3 Hibs. 1297 surveys were mailed and there was no additional followup. There was a 24% response rate. The immunization rate was 89%, much higher than previously reported for Houston.

In Houston, articles in the local newspapers stated, "CDC reports Houston to have one of the lowest immunization rates in the nation."

The Center for Disease Control conducted a retrospective analysis of school age children for vaccination levels at their second birthday for nine cities (1). The proportion of children who were up-to-date with valid doses by their second birthday, based on the 4 DTP:3 OPV:1 MMR schedule was 10% in Houston. When up-to-date vaccination levels were determined without application of the strict definitions for timing of valid doses, the coverage rates increased by 1% to 6%.

The mail survey results were suspicious even though the different study designs account for some of the difference. There is some evidence that the HMO's have higher immunization rates than the community as a whole. A study of six HMO's in the Dallas Fort Worth Area reported up-to-date immunizations in two year old children in 1993 and found immunization rates to be 47% (2). A similar study of six HMO's from the report card project reported average immunization rates at 79% for two year old children in 1993 (3).

The Houston HMO study reported one of the highest HMO immunization rates in a community with one of the lowest reported rates.

How valid and reliable is the mail survey instrument? A validation study by medical record review of immunizations was conducted.

STUDY OBJECTIVES

- o To compute an immunization rate based on a medical chart review for a Houston area Health Maintenance Organization insured children who were one year old in 1993.
- o To assess the validity of the immunization rate based on the mail survey.
- o To compare the HMO data with the regional data.

STUDY DESIGN

A medical record review was conducted on a systematic sample of 247 children selected from the logs of the immunization mail survey. The original survey was sent to the parents of each child who turned one between July and October of 1993. The survey was sent during the month the child had his/her one year birthday. Both responders to the mail survey and non-responders were included.

To achieve the second goal (response bias analysis and accuracy analysis) another 33 who responded to the first study were selected systematically from the initial survey respondents. With this addition, the power is .8 to detect a 15% difference in immunization rates between the respondent group versus the non-respondent group.

Identification of Immunization Status

For both the survey and the medical record validation, a child is considered immunized if he/she had 3 DTPs, 2 OPVs, and 3 Hibs by one year of age.

In the medical record review, these immunizations are counted as valid if the date is listed in the chart. Shots past the one year birthday were not counted.

Medical Record Review

Each child's current and historical Primary Care Physicians (PCPs) were identified and contacted by letter and then by telephone. If there was no record of the immunization, these doctors were asked if there was a notation in the chart of a previous doctor. If there was no notation, the parents were contacted by telephone and by letter and asked where their child received his/her immunization. All identified non-HMO physicians were contacted by telephone. A child was counted as immunized if the office record noted the date of immunization.

Regional Comparison

The literature was scanned to identify studies with a similar definition of immunization. Local and state health departments were contacted to identify studies that may not have been published.

RESULTS and CONCLUSIONS

The immunization rate using medical records as the source was 76%, lower than the survey percent of 89%.

Validation Analysis

To evaluate response bias, the sample was divided into two groups, respondents to the mail survey versus non respondents. For the respondents, the immunization rate was 79% and for the non-respondents the rate was a little lower at 74%. Using a Chi-square test, the difference was not significant (Chi-square=0.64, p=0.42, Table 1).

Discrepancies between the medical record review were analyzed. 91 medical record study members responded to the initial survey. Of these, the "immunization status" from both sources for 75 were the identical. There are two types of discrepancies: survey notes "immunized" while the medical record review indicated "not immunized" or the reverse. Of the 91, 14% (13) had the former discrepancy and 3% (3) had the latter. These differences were not due to chance according to the McNemar test, p=0.02, Table 2. This test is sensitive to differences in imbalances in the types of discrepancies.

C. Hanson, MD, Texas Children's Hospital, found similar results in a discrepancy analysis of a prospective immunization survey of children who were 18 to 24 months of age during January through May, 1993 (4). Of the parents who reported their children as fully immunized, only 43% were accurate while 98% of the parents who

identified their children as lacking immunizations were accurate.

Regional Comparison

Most of the immunization studies in the literature listed results for two year old children and not one year old children. To find a regional comparison, city, county, and state health departments were called. Two studies which have not yet been published were identified with results of children who are one year of age.

The Texas Health Department conducted a population based study of all Texas children under age two in 1994 (5). A preliminary analysis found that 70% of the one year old children were up-to-date by their first birthday with 3 DTPs and 2 PVs.

In a retrospective study conducted by the Immunization Division of the Texas Department of Health in 1994, 60% (95% C: 56% to 64%) of the Texas kindergarten children were immunized with 3 DTPs and 2 polio vaccines within 366 days of birth (6). In the latter study the birth cohorts were 1988-89 while the HMO study birth cohort was 1992.

According to this immunization criteria and using the medical record review data, the immunization rate for the Houston HMO was 81% (95% CI: 77% to 85%). The Houston HMO has a statistically significant higher rate than the state as a whole using either study as the comparison.

The Houston immunization rate is lower than the state as a whole. In 1993 the Immunization Division of the Texas Department of Health conducted a study similar in design to the 1994. For two year old children, the immunization rate was 42% for the state as a whole and for the Houston region the rate was 31% in 1993 (7).

This is the lowest regional rate in the state.

The Houston HMO had a higher immunization rate than the state as a whole because HMO's reduce the effect of two common barriers. The costs are relatively inexpensive. Typically, the charge is an office co-pay of $5 to $10. The city and county has 55 mobile sites and 12 (plus county) health centers with free locations who immunize children on a first come first serve basis. This HMO has approximately 500 physician practitioners and 170 pediatricians in the Houston area who schedule appointments.

QUALITY IMPROVEMENT ACTIVITIES

Even at 76%, the immunization rate for one year old children needs improvement. Three major efforts were implemented by the HMO to increase immunization rates.

An article was written in the member magazine to emphasize the ramifications of not immunizing. A tear out chart that can be updated and kept in a mothers purse or father's wallet was inserted in the magazine. The parent was encouraged to have the physician fill out the card.

A physician letter was published in the provider newsletter. This letter emphasized the importance of record keeping which would allow the physician to easily tell whether the child was "up-to-date" or not.

A reminder post card was developed and sent to the parents of one year old children.

The reasons for giving a tear out chart and for sending the reminder postcards are supported by research. A recently published study of immunizations in an HMO has found that more than one third of parents did not know when the next immunization was due (8). The authors concluded that "In managed care settings, which may cover increasing numbers of children, interventions are needed to better inform parents when immunization rates are due."

FUTURE STUDIES

Two future studies are planned. They will evaluate the immunization rates for two year old children in 1994 and in 1995 to determine the effects of the improvement activities.

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Table 1.

Response Bias Analysis
Medical Record Review Immunization Status by Response to Survey

	Immunized	Not Immunized
Nonrespondents	115	41
	73.7%	26.3%
Respondents	72	19
	79.1%	20.9%

Chi-Square	Value	DF	Sig.
Continuity C	.64	1	.42
Likelihood Ratio	.92	1	.33

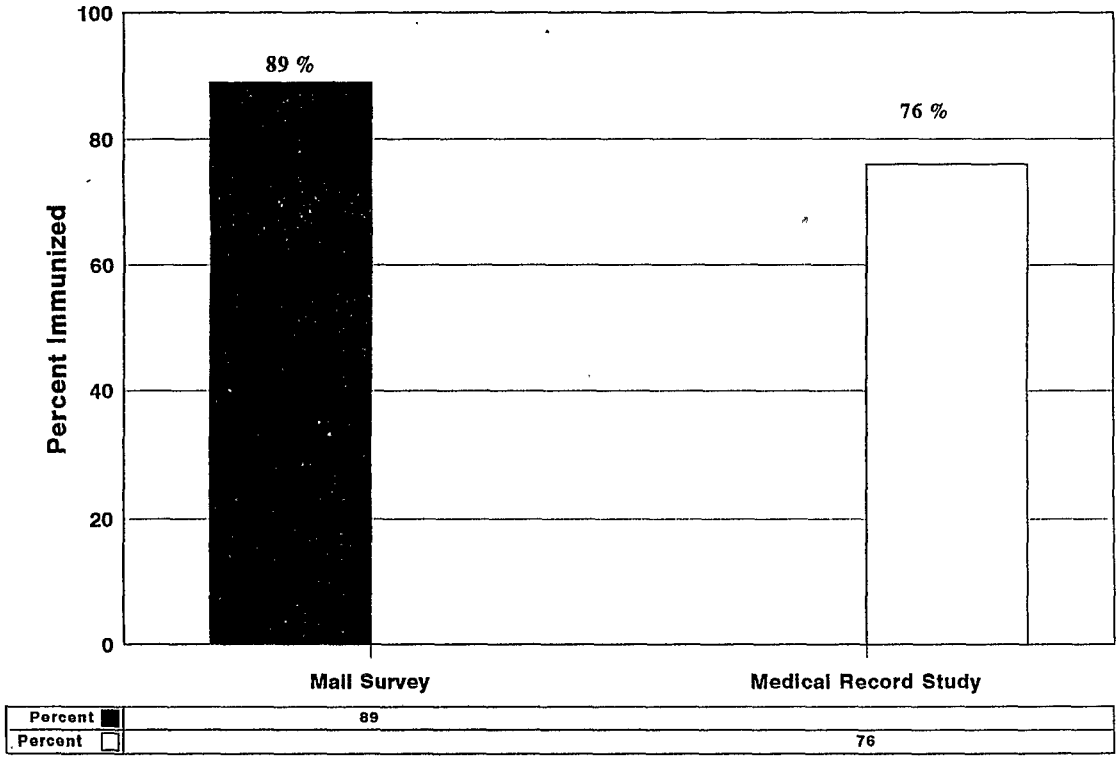
Table 2.

Discrepancy Analysis
Comparison of Responses-Survey vs Medical Record Review

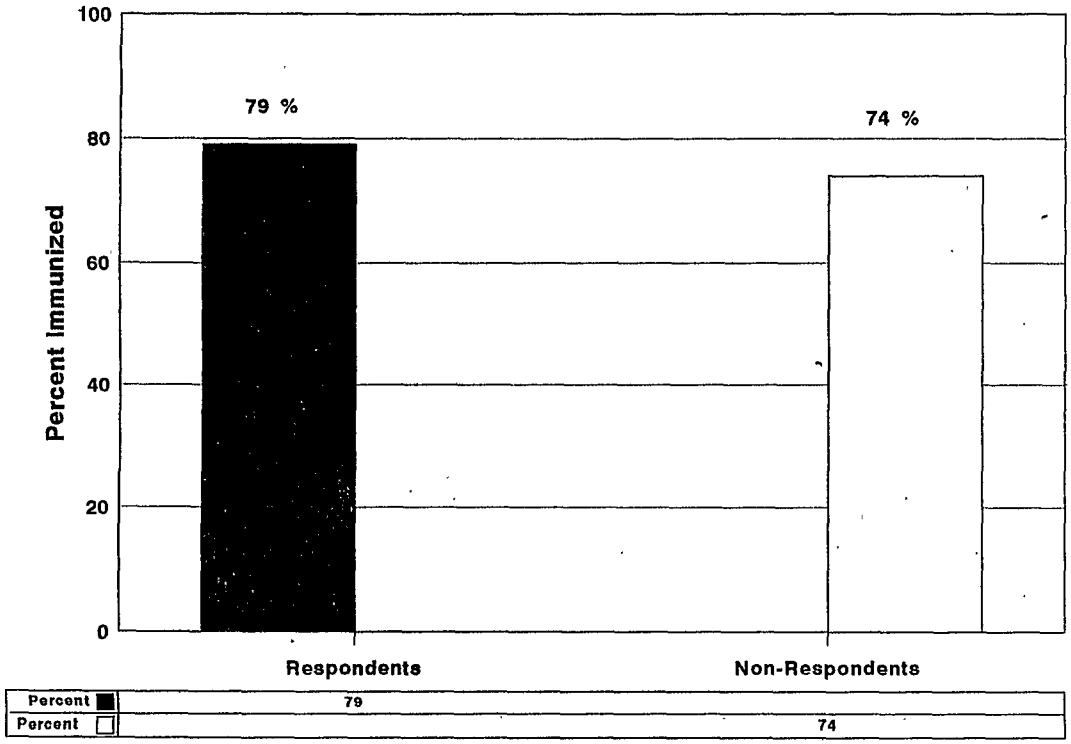
	Immunized Yes	Medical Record No
Immunized Survey		
Yes	69	13
	76%	14%
No	3	6
	3%	7%

Binomial 2-Tailed P .02
Cases 91

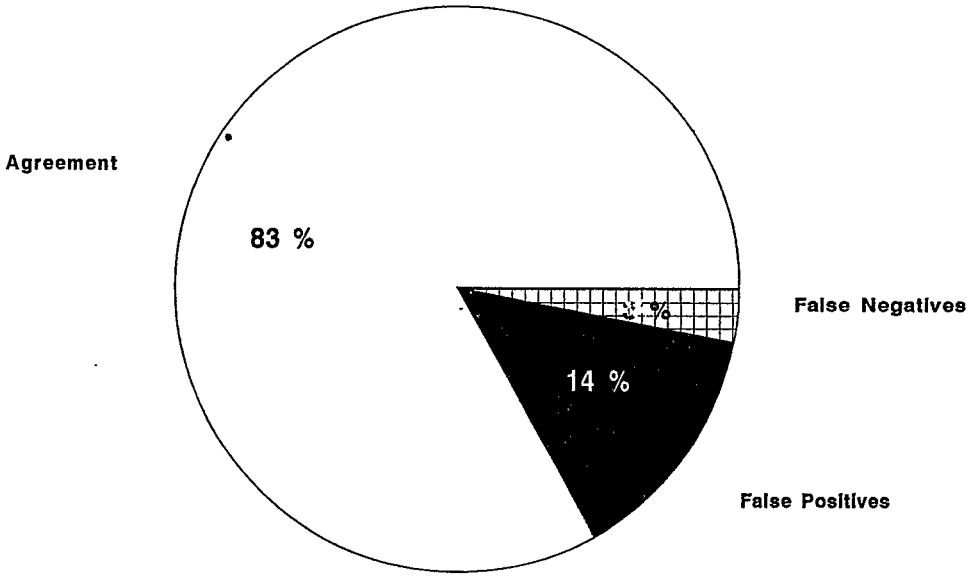
"Mail/Survey" Greater Than "Medical Record Study"



No Response Bias
Mail Survey

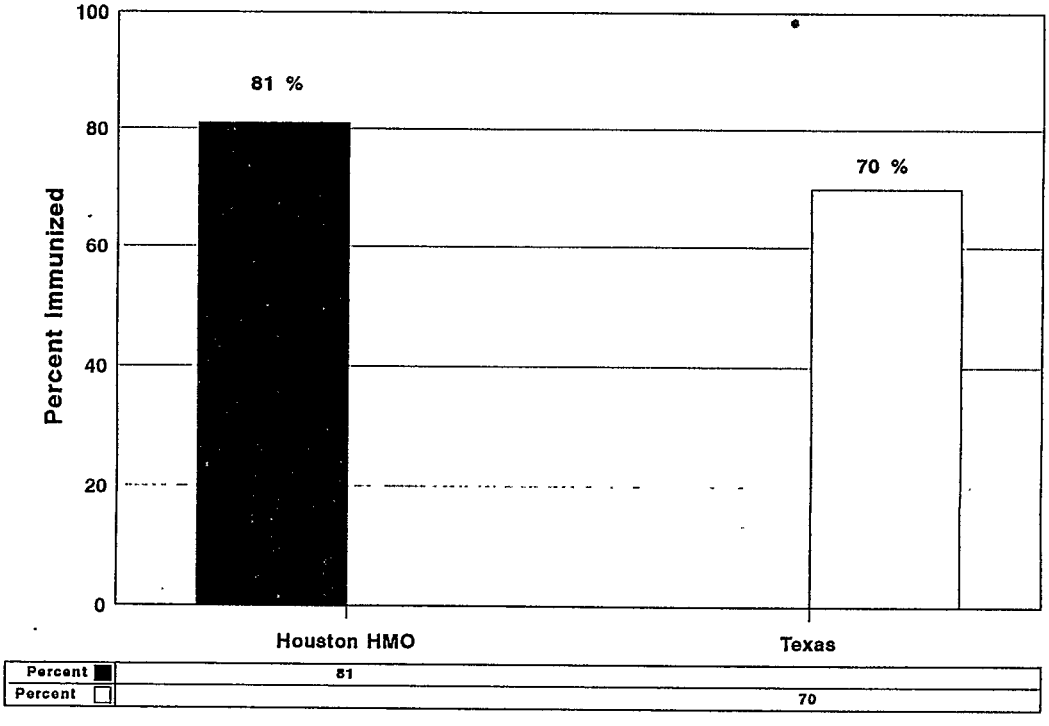


False Positives
Inflate Survey Immunization Percent



Discrepancy Analysis

HMO Percent Is Higher Than State Percent



Immunized: 3 DPT's and 2 PV's

MONITORING COMPLIANCE WITH IMMUNIZATION PERIODICITY SCHEDULES USING 1989 MEDICAID CLAIMS DATA[1]

Norma I. Gavin, Research Triangle Institute
Elicia J. Herz
Katherine Sredl
Donald Schroeder

INTRODUCTION

The American Academy of Pediatrics (AAP) recommends that by 18 months of age all children complete a schedule of four doses of diphtheria-tetanus-pertussis (DTP) vaccine, three doses of oral polio vaccine (OPV), and a single dose of measles-mumps-rubella (MMR) vaccine.[2] A fifth dose of DTP and a fourth dose of OPV are recommended for children between the ages of four and six years. Compliance with immunization periodicity schedules is important to ensure an adequate antibody response to each vaccine and the earliest possible protection from preventable childhood diseases.

Studies have found that, despite the net social benefit of childhood vaccines, many children in the United States do not complete this series of immunizations at the recommended ages. Estimates of the percentage of two-year-olds current in their immunizations range from lows of 40 to 50 percent to highs of 70 to 80 percent with noted pockets of lower rates in inner urban and rural areas (Lewit & Mullahy, 1994; Zell et al., 1994; Hueston et al., 1994; Bobo et al., 1994). Studies have also found that children in families with restrictive household resources, measured by available adult time, more than one child, and low maternal education, have lower immunization completion rates (Frank et al., 1995; Bobo et al., 1994). Thus, despite the elimination of financial barriers for vaccinations, Medicaid children are at high risk of incomplete immunization in their preschool years.

Medicaid claims are a potential low-cost source of data for monitoring Medicaid children's compliance with immunization periodicity schedules. However, they have limitations. The claims databases reflect only immunizations billed and paid through the Medicaid program. Thus, they would not capture any immunizations children received when they were not enrolled in Medicaid or immunizations children received during periods of Medicaid enrollment that were paid through other public or private sources. The extent to which Medicaid claims data are missing immunization data for child enrollees has not been investigated.

The objective of this research is twofold: (1) to determine whether Medicaid children are receiving childhood immunizations at the recommended ages; and (2) to evaluate the usefulness of Medicaid claims data for monitoring children's immunization status. We examine Medicaid claims for DTP, OPV, and MMR vaccinations among children under seven years of age in four states during 1989.

DATA SOURCES

The Medicaid enrollment and claims database, known as the Tape-to-Tape files, is the primary data source for this analysis. In particular, we used 1989 enrollment and claims data for California, Georgia, Michigan, and Tennessee. We took the number of months of Medicaid enrollment in 1989 from the enrollment files and the number of immunizations by type from the claims file, where immunization type (i.e., DTP, OPV, and MMR) was identified from procedure codes.

We also had data from the forms that providers filled out during screening visits for the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program. EPSDT, the pediatric component of the Medicaid program, is designed to provide comprehensive, periodic screening services, as well as services to correct health problems identified through the screening services, to all Medicaid-enrolled children. For Tennessee and Michigan, providers indicated whether children were up-to-date in their immunizations. The Tennessee form had a single question referring to all childhood immunizations while the Michigan form had separate questions for each of the major childhood immunization types.[3]

METHODOLOGY

To assess Medicaid children's compliance with the AAP periodicity schedule, we assigned a set of weights to each child in the database. The weights reflect the child's expected number of immunizations by type during the child's enrollment period in the analysis year. To compute the weights, we determined how many vaccinations of each type the child should have had during the year given his/her age in months at the end of the year. (See Table 1.) Then, to account for the fact that many children were enrolled for less than the full year, we multiplied this number by the percentage of months in the year during which the child was enrolled. This adjustment assumes that the child is equally likely to receive immunizations during periods of Medicaid enrollment and periods of disenrollment.

TABLE 1
American Academy of Pediatrics
Immunization Periodicity Schedule, 1989

Age Group	Immunizations
< 1 year	3 DTP at 2, 4, & 6 months
	2 OPV at 2 & 4 months
1-2 years	1 MMR at 15 months
	1 DTP at 18 months
	1 OPV at 18 months
3-6 years	1 DTP at 4-6 years
	1 OPV at 4-6 years

We then summed the weights to obtain the total expected number of immunizations among the child population under study. This figure is the denominator for our compliance rate. The numerator is the sum of all immunizations received by the population as reflected in the number of billed immunizations in the claims data.

$$\text{Compliance Rate for } j = \frac{\text{Actual Number of } j\text{th Immunization}}{\text{Expected Number of } j\text{th Immunization}} = \frac{\sum_i I_{ij}}{\sum_i \bar{I}_{ij}} \times 100$$

where

$$\overline{I}_{ij} = \frac{\text{Months } i \text{ Enrolled}}{\text{Months } i \text{ Alive}} \times \text{Number of } j\text{th Immunization Recommended for } i$$

An overall compliance rate is computed by summing both the numerator and the denominator over the types of immunizations:

$$\text{Overall Immunization Compliance Rate} = \frac{\sum_j \sum_i I_{ij}}{\sum_j \sum_i \overline{I}_{ij}} \times 100$$

Because a number of children received immunizations later than recommended and, therefore, were not truly in compliance, we recomputed the compliance rate counting only those immunizations that fell within the recommended age range. We show both sets of rates rather than just the age-appropriate rates because the extent to which the Medicaid program allows children to catch up on missed immunizations is an important measure of the success of the Medicaid program in reaching children who otherwise would not receive these immunizations.

Because most childhood immunizations should be received before the age of six years and because most states require proof of immunization for school entry, we limit our presentation to children six years of age and under. We break this age range out into three age groups: (1) children under one year of age — the age at which the greatest number of visits to the physician's office are required for immunizations; (2) children from one to two years of age — the end of the target age range for the Healthy People 2000 goal of 90 percent compliance; and (3) children from three to six years of age — the ages at which children enter school.

Then, to determine the extent to which low compliance rates are due to missed immunizations versus missing data, we computed immunization compliance rates for children who had at least one EPSDT visit during 1989 and compared them to the percentages of children that providers found to be up-to-date in their childhood immunizations by their last EPSDT visit that year.

FINDINGS

Table 2 shows the overall compliance rates, computed with all DTP, OPV, and MMR vaccinations. Compliance increases with age. Infants who have the greatest number of recommended immunizations have the lowest immunization compliance rates while children aged three to six years have the fewest number of recommended vaccinations and the highest compliance rates. In fact, the compliance rates for the three-to-six-year-olds is greater than 100 percent, suggesting that these children received more than the recommended number of immunizations for their age group. Presumably, these children are catching up on immunizations missed in their earlier years in order to qualify for school entry.

TABLE 2
Immunization Compliance Rates for 1989
Using All DTP, OPV, and MMR Vaccinations

State	< 1 Year	1-2 Years	3-6 Years
California	46.0%	79.0%	126.5%
Georgia	42.8	72.3	119.6
Michigan	38.0	60.5	105.9
Tennessee	49.3	71.3	93.6

This hypothesis is confirmed in Table 3 where we present immunization compliance rates based only on age-appropriate immunizations. The rates for three-to-six-year-olds drop 25 to 40 percentage points in each state. The rates for one-to-two-year-olds also drop substantially, suggesting that these children also received immunizations missed during their infancy.

TABLE 3
Immunization Compliance Rates for 1989
Using Age-Appropriate DTP, OPV,
and MMR Vaccinations Only

State	< 1 Year	1-2 Years	3-6 Years
California	44.4%	56.7%	85.7%
Georgia	41.5	53.0	83.9
Michigan	37.2	44.1	67.1
Tennessee	46.6	52.7	67.9

To determine the extent to which Medicaid children received immunizations under other programs in 1989, we computed compliance rates for the subset of Medicaid infants and children aged one to two years with visits through the EPSDT program. In Table 4, we show these rates and the percentages of children that providers noted were up-to-date in their immunizations at their last EPSDT visit in 1989.

TABLE 4
Immunization Compliance Rates[1]
for EPSDT Participants
and Percentage of Participants Up-to-Date
in Immunizations
According to Their EPSDT Screening Form in 1989

State	< 1 Year	1-2 Years	3-6 Years
Michigan			
Compliance rate	47.5%	57.9%	—
Percent up-to-date	80.5	75.7	85.5
Tennessee			
Compliance rate	63.8	73.4	—
Percent up-to-date	82.5	78.4	80.5

[1] Only age-appropriate DTP, OPV, and MMR immunizations have been used to compute these compliance rates.

These data show that, for infants with at least one EPSDT visit in Michigan during 1989, nearly 48 percent of recommended immunizations were provided through the Medicaid program. In Tennessee, Medicaid-enrolled infants received almost 64 percent of recommended immunizations through the Medicaid program. At the same time, more than 80 percent of infants in both states were reported to be current in their immunizations by their last EPSDT visit during the year — that is, they reportedly received all of their recommended immunizations. If all of these immunizations were billed through Medicaid, we would expect to see a compliance rate over 80 percent. Because the computed compliance rates are lower, these children must be obtaining their immunizations through other programs.

The discrepancy between the percentage of billed immunizations and the percentage of chil-

dren who had received all their immunizations was smaller for children aged one to two years. Nevertheless, these data indicate that, in Michigan at least, one-to-two-year-olds were also receiving a substantial number of immunizations outside of the Medicaid program.

Table 5 shows that, in Michigan, this pattern was consistent across the three major types of childhood immunizations. In addition, the 70 percent of one-to-two-year-olds and the higher 93 percent of three-to-six-year-olds current in the MMR vaccination confirm that the older children are receiving immunizations missed during the earlier years. Recall that the AAP recommends an MMR vaccination at age 18 months, but none from age three to six years (see Table 1).

TABLE 5
Immunization Compliance Rates[1] for EPSDT Participants and Percentage of Participants Up-to-Date in Immunizations According to Their EPSDT Screening Form by Immunization Type in Michigan 1989

Type of Immunization	< 1 Year	1-2 Years	3-6 Years
Diphtheria-tetanus-pertussis			
Compliance rate	45.0%	61.5%	-
Percent up-to-date	80.8	79.0	86.3
Oral polio vaccine			
Compliance rate	50.3	58.5	-
Percent up-to-date	82.2	80.0	86.9
Measles, mumps and rubella			
Compliance rate	-	43.1	-
Percent up-to-date	-	70.2	92.7

[1] Only age-appropriate DTP, OPV, and MMR immunizations have been used to compute these compliance rates.

CONCLUSIONS

Two major conclusions can be drawn from this analysis. First, Medicaid children received a substantial number of immunizations that were not billed through the Medicaid program. Thus, while Medicaid claims data can be used to show trends across groups of children and perhaps over time, they cannot be used to determine immunization levels among a population of children.

Second, a substantial number of immunizations beyond those recommended for their age group were received by Medicaid children aged three to six years. These billings appear to be a result of children's catching up on missed immunizations from earlier ages so that they may enter school. Thus, the extent to which children aged three to six years receive immunizations beyond those recommended for their age group provides a measure of the extent to which children missed immunizations at earlier ages. Tracking this measure over time may allow us to see whether we are getting closer to the national goal of 90 percent of two-year-olds fully immunized by the year 1996.

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NOTES

1. This analysis is part of the baseline year findings of a larger study, funded by the Health Care Financing Administration, that is designed to investigate the impact of provisions in the 1989 Omnibus Budget Reconciliation Act affecting Medicaid services for children.
2. The AAP also recommends a Haemophilus influenza type b (Hib) vaccination at 18 months of age. However, this recommendation had just been established in 1989 and was not yet fully implemented in physicians' practices.
3. California's form also asked providers to check whether children were up-to-date in their childhood immunizations by type of immunization. However, the high rate of missing data in these variables (greater than 22 percent) made them hard to interpret; therefore, they are not shown here.
4. Compliance rates for three-to-six-year-old EPSDT participants were not computed because these rates would not be valid for interpretation. Not all children in this age range are required to have immunizations each year. Thus, including only children with EPSDT visits and, therefore, a high probability of having an immunization would bias the rate upward. Furthermore, the enrollment duration adjustment assumes that the child is equally likely to have an immunization during periods of enrollment and disenrollment. This is obviously not true if the sample is restricted to children with EPSDT visits.

EFFECTS OF A STATEWIDE REGISTRY ON IMMUNIZATION SURVEYS

David Lohrisch, MS State Dept. Of Health
F. E. Thompson,Jr., Robert Hotchkiss,
Liane Hostler

The goal of the nation for the year 2000 is to have a 90% immunization rate of two year old children. The unchallenged measurement tool for this objective is a survey of the two year old birth cohort. There may be a better way to measure this and other critical points in childhood vaccination using an immunization registry. However, the development and use of a registry itself creates new problems which could limit the usefulness of a registry.

Most immunization programs rely heavily on surveys to provide them and the immunization workers in the field with the vital data they need to monitor and improve immunization rates. In Mississippi, all health department clinics utilize the same state provided data. Apart from a single report each month of new births, all of the remaining data for program management comes from surveys and reports completed by parties interested in the effort.

Current Immunization Information System

Birth printout from vital statistics (sanitized). This provides a snapshot of the population at that time, which gets less accurate as the cohort ages. The printout is not complete, as there are always delayed registrations. This is manual and does not feed an automated system that will reduce time and errors identifying children who miss vaccinations.

Yellow shot card for each health department patient who receives childhood vaccines. In Mississippi clinics, these cards are filed by date to serve as a tickler for follow-ups and reminders. These cards are manually maintained and are subject to loss and misfiling in addition to data capture errors. These cards are only completed in the health departments for clinic patients, and not available to the staff for children of private doctors and clinics. The cards are also not readily available across clinics. Thus the need for a central registry.

Vaccine Administration Record. This federally mandated record is completed by the nurse for each vaccine type showing batch/lot, site of administration, manufacturer , as well as warnings. This form captures data available in the registry and is a potential for elimination.

Yellow card maintained by parents. This card is completed by the nurse each time a shot is given to the child, whether in a health department clinic or in a private office. This card is subject to loss and more frequently to being forgotten at the visit. The information may not be current and is definitely not readily available to immunization workers to determine status.

Blue and other colored compliance forms. These forms are completed by providers and serve as formal notification to institutions that the child is compliant. They contain minimal data and are either retained by the institution or lost by the parents.

Two year old survey. This survey is of the birth cohort at 24 months of age and is the basic measurement tool for programs across the country. In Mississippi, this survey is stratified across the nine public health districts and then randomly sampled based on population and immunization levels. Districts with low populations and poor immunization levels have the highest sampling rate of 7.5%. The lowest rate is 1.9% for a district with high population and good immunization level. Statewide 1,343 children were sampled out of a cohort of 41,000. The limitations of this survey are errors in data collection, incomplete data due to poor documentation and delays due to the nature of the survey. The majority of the problems with immunization rates in Mississippi occur between the first and second birthdays. Since all immunizations should be completed by the 15th month, and the second survey is done up to 35 months of age. There is a 20 month lag between scheduled immunization and review. Because it is a sample, it is not useful for tracking of individuals but only to provide directions for changes in the system.

School Compliance Reports - Preliminary and Final. All schools in the state complete a report manually which details by school, grade and certificate type, the status of students. This report provides to the immunization program information that is already known to the health department clinics for at least 50% of students. The agency has no systems is place that can retrieve these data. Similarly, neither the schools nor the state education department have systems to generate these data.

First Grade School Validation Survey. Based on the school compliance reports, a stratified random sample of schools and first grade classes is drawn and students sampled within these classes. The program workers then determine the status of the children in the sample. At the same time, the status of these students at 2 years of age is also determined retrospectively. This sample frame generated 5,500 students last year. This sample also helps measure the rates at the two check points and determine system points of failure.

College Immunization Survey. This is a random sample of first time admissions to colleges in the state for mumps and rubella compliance. The sample of 20% in 1994 generated 4,345 student records that were followed back by immunization workers.

Child Care Validation Survey. This survey is a random sample of 10% of the child care facilities licensed by the state. Within each facility, 20% of the children over age two were chosen for a total sample of 1,143. This survey obviously measures the levels in the day care centers that are prime targets for disease transmission.

Statewide Immunization Registry

The obvious solution for a centralized state like Mississippi is to develop a statewide immunization registry. Several factors converged in 1995 to enable us to get into a statewide registry. The agency had been working for several years to automate its clinic functions, one of which was immunization. The basic system was completed and installed statewide by early 1995. At the same time, the state legislature mandated a statewide immunization registry effective January 1995. This law required all doctors giving immunizations to report data to the state registry and to be provided current status from the registry. The internal clinic system (PIMS) is integrated for all health department programs, including immunization, which meant that it would have to be modified to protect non-immunization data from external users. This could not be done immediately, so the immunization program has provided for phone operators and mail-in reporting of immunizations until the system has been converted. The state is in a good technical position to move into a statewide registry because it already provides

over 75% of all immunizations given, which with our rate of 73%, amounts to 55% of the total population.

The software already provides for the agency the basic features of a registry such as data collection, reminders, internal logic to determine validity of doses, doses administered reporting and VFC reporting. Before external providers could utilize the system, firewall software had to be written to protect internal clinic data from the external users of immunization only data. This project is being funded by CDC through the immunization program and has been stalled for several months. Once this has been done, the real problem begins with training the several hundred doctors' offices who give shots how to use the system.

The registry has the potential to drastically change the way immunization status is determined as well as improving the efficiency of the immunization program workers.

The system will eliminate the need for blue slips when the schools can access the system. The system already has automated blue slip production. It also can potentially eliminate the need for birth certificate hard copies for school entry. The major barrier to implementing this technology is the reduction in revenue to the vital statistics program. The system will produce call lists, record pull lists and any other report which can be logically defined to the system. This will give the program staff the ability to focus the attention on any group of the population which they feel can improve.

Automation of the system has the potential to reduce the paperwork in the clinics. The yellow tickler cards and the vaccine administration record are candidates for elimination. The major problem at this stage is procedural, the current form requires the nurse's signature. The rest of the data on the form is being captured in the registry. The benefits to the parents in not having to worry about the whereabouts of their yellow card are many. Imagine being able to have any doctor or nurse, school or daycare pull up the status of my child from any PC.

The surveys will change dramatically because the population is basically in the system, at least for the two year olds and the six year olds. The registry has all of the health department records in the system from 1992 forward. Later this year we will receive from Social Security Administration (SSA) a list of all records from 1990 forward. This will also help populate the registry. The immunization field workers will continue to review records for completeness, but the objective will be redefined from measurement to one of data quality and completeness.

Problems and Opportunities of a Statewide Registry

Accuracy and Completeness. The registry will be built from the database for newborns, the vital statistics birth file. This file in Mississippi is mostly created electronically via the EBC process, in itself a more accurate way of obtaining data. These data are then sent to SSA where the Social Security Number (SSN) is created and added to the records of those children whose parents request electronic generation of SSNs. This file when received back in the state, contains the accurate name, date of birth and SSN. The population of the cohort is therefore built from accurate data with no possibility of error. Errors can only come from changes in items which are not reflected in the file or from incorrect immunization events recording in the file. Of course, migration over time will also be a possible source of errors.

The other issue for Mississippi is the high percentage of immunizations given at the health department clinics. Currently, about two thirds of all immunizations are given in these locations. All of those events are recorded in the PIMS based registry. This means that as long as internal data quality is high, the program field workers can concentrate on improving the quality of the 30 % not internal to the health department.

Single Database. The system is based on a mainframe which contains the one file for the only registry for the state. There are no separate files to keep in synch and no multiple queries to make to completely identify or exclude a child. This makes the system simple to develop around. There is only a computer system to relate to and only one file to look up. Training and setup for retrieval is simple, although the mainframe has several options for access.

Mainframe Based. The mainframe has some advantages. It has several different options available for access from almost any type of computer system. The technology is readily available for linkages from mainframes, minicomputers, server based LANs and single PCs. The state mainframe supports access from PCs via asynchronous dialup and via TCP/IP Internet type connection. The system is also online to the Internet and can be addressed this way. The mainframe is also a reasonably secure system, particularly for the medium level of security data in a registry. This system is supported already and the agency has minimum work to do in order to maintain the system on the mainframe.

System Interfaces. There are many larger private operations that are automated and would prefer to have automated interfaces to the registry. This is technologically possible, but will take a concerted effort on the part of the immunization program or the private clinics. The software developer of the registry has a common interface protocol defined that will make it easier for this type of high level interface to be implemented.

Private Physician Training. There are about 400 private physicians in Mississippi who routinely give immunizations. The training effort for the staff in these offices is substantial, both initially and ongoing. While the software is not complicated or difficult to learn, there is still a learning curve for the office and support staff in the physicians offices. We would be pleased if all offices could be trained initially within two years. At this point, the staffing for this effort has not been acquired.

Education Department Linkage. Exploratory meetings have been held with the State Department of Education who would like to develop an electronic student record on a statewide basis. This record would be maintained by the State department and accessed by all schools in the state. When students transfer, the electronic record would still be available. A portion of this record contains immunization and birth certificate data. Obviously, these data should come from the registry, and could either be transferred to the education file or simply be a link between the two systems. Within the next two years, all of the schools in the state will be online to the education system via an Internet type network. During that same time frame, the registry should be complete for over 90% of the birth cohort, and 75% complete for the 5 year old cohort. It is possible that K5 children will be checked for date of birth and Immunization compliance without having to access a health department system directly.

Junior and Senior College Systems. When this concept was presented to a group of college presidents, they wanted access to the system right away. They are not willing to wait for 15 years for the registry to age gracefully so their age group will be represented. This offers us an opportunity to see if the colleges can find a way to enter their freshmen's data as their staff are determining compliance. We will be looking for funding to provide to colleges for historical data entry. We have over half of the data, which we can get in easily with some data entry help.

Students from colleges may be better used to track down the records of the private providers.

Automation of Private Offices. This process will be tedious and potentially very expensive, based on the cost per child immunized. Other registries have found that providing software that will do more than just access the registry can increase physician involvement. The immunization program will be working to identify software providers who will sell us a statewide license with an interface to our registry. The vendor will also install and train worker in the use of the system.

Day Care Facilities. The 12 to 24 month old children are not in school during this time, but either at home or in day care facilities. While the state department of health licenses these facilities, there is no automated record of the children in these facilities. Most of the facilities are not automated, nor are they expected to be in the near future. We anticipate that our inspectors, both day care and immunization, will be equipped with laptops that will be network enabled and could verify the status of day care children during their inspections. The larger facilities may be sampled, but the smaller ones could be 100% checked for compliance using the registry.

Data Quality Control. Followup reviews of historical immunization data entry in the health departments have shown large percentages of data entry errors. Some of these are unavoidable while others are definitely due to carelessness. The degree of errors has made us rethink how we will ensure the quality of the data being entered. For our own employees (all staff in the health department clinics are state agency employees) we will incorporate data quality standards into performance appraisals. We will also require nurses to review and check data entry, particularly the historical data. Based on these data, we will look toward contractors for the bulk of future historical data entry.

SUMMARY

The immunization program samples annually with labor intensive follow-back over 12,000 records each year. The state immunization rate exceeds 70% on a base of approximately 40,000 births. If the existing workers were to focus their follow-back efforts on the missing 30%, this would approximate the 12,000 that are currently being sampled. This is ideal, but the reality is that the field staff will have to continue to sample the population file to ensure that the quality of the data in the registry file is of acceptable quality. The staff will shift the focus of the followback effort from measurement to quality control.

The effort required to bring the majority of the private providers is significant, but necessary to make the registry fully productive. The state will have to experiment with various incentives which will encourage the participation of the private sector. Historical data entry has been a major impediment, but innovative funding and contract sources may speed up this vital phase of the registry's development.

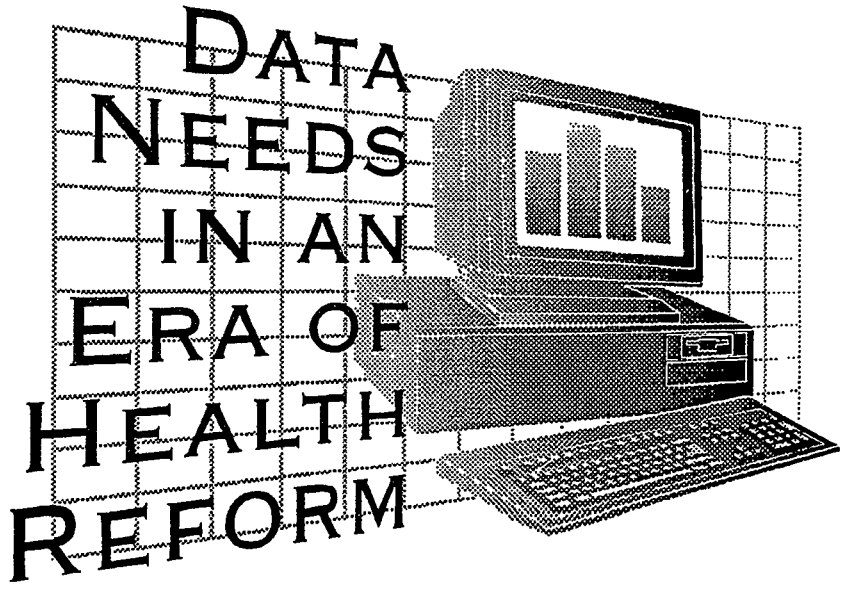
OVERVIEW OF IMMUNIZATION SURVEYS OF TWO-YEAR OLDS: COLLABORATIVE EFFORTS OF THE NATIONAL CENTER FOR HEALTH STATISTICS AND THE NATIONAL IMMUNIZATION PROGRAM

James T. Massey, National Center for Health Statistics

Paper not available for publication.

Session E

International Reporting of Injuries



THE USE OF INTERNATIONAL COMPARISONS IN INJURY RESEARCH

Gordon S. Smith, Johns Hopkins University

Paper not available for publication

NON-FATAL FIREARM INJURIES : NEW ZEALAND COMPARED WITH USA.

John D Langley, University of Otago
Joseph L Annest
Stephen W Marshall
Robyn N Norton

Aim: To compare the epidemiology of serious non-fatal firearm injury in New Zealand (NZ) to that in United States of America (USA).
Method: New Zealand cases were selected from the New Zealand Health Information Service's hospital inpatient data files for the period 1979 to 1992 inclusive. USA inpatient cases were selected from the USA National Centre for Injury Prevention and Control (NCIPC) Firearm Injury Surveillance Study.
Results: At 22.0 per 100,000 population, the USA has an inpatient injury rate for nonfatal firearm injuries 8 times that of NZ. In the NCIPC inpatient series 35% of the incidents involved handguns whereas in the NZ series less than 2% involved handguns.

In the NZ series 64% of the injuries were considered to be due to unintentional events whereas they accounted for only 13% in the NCIPC series with assault being the main contributor at 61%.
Conclusions
The differences between USA and NZ in inpatient rates for overall nonfatal firearm injuries and for those associated with assaults may be related to firearm policies and socio-cultural differences. This needs to be investigated further through epidemiologic studies and international comparisons.

Introduction

Mortality and morbidity due to firearms are the subject of considerable controversy, especially in USA. Much of the debate has focused on the high and unnecessary number of fatalities due to firearms. At 14.9 per 100,000 population USA has one of the highest firearm mortality rates in the world (Kochanek & Hudson 1994).

Until recently national estimates on non-fatal firearm injuries have not been available. The aim of this paper is to compare key findings from recent NZ and USA population based studies of non-fatal firearm injury. This comparison was stimulated by the International Collaborative Effort on Injury Statistics (NCHS 1995).

Method

For the purposes of this study serious non-fatal injury was operationally defined as any injury which did not result in death but which required inpatient treatment in a public hospital.

A firearm related injury was defined as any injury which resulted from the discharge of a firearm. Injuries such as those due to the direct handling of cartridges, for example, were not included. Similarly, injuries due to airguns, stun guns, flare guns, nail guns, and other such devices were also excluded.

The method for selecting cases for the NZ series is described in detail by Langley et al (1995). Very briefly, cases were selected from the New Zealand Health Information Service's (NZHIS) hospital morbidity data files for the period 1979 to 1992 inclusive. All discharges with the following E-codes were selected: E922 Accident caused by firearm missile; E955 Suicide and self inflicted injury by firearms and explosives; E965 Assault by firearms and explosives; E985 Injury by firearms and explosives, undetermined whether accidentally or purposely inflicted; and E970 Injury due to legal intervention by firearms. Free-text descriptions associated with each case were reviewed in order to code the type of firearm and eliminate misclassifications. Readmissions to hospital for the treatment of the same injury were excluded.

Estimates for the USA inpatient series were obtained from a series based on emergency department visits (NCIPC Firearm Injury Surveillance Study). The method for this study has been described in detail by Annest et.al. (1995). Very briefly, data were obtained from medical records for all firearm-related injury cases identified using the National Electronic Injury Surveillance System (NEISS) during the study period of June 1, 1992-May 31, 1993. NEISS data is collected at 91 hospitals and provides a stratified, representative probability sample of all attendances at USA hospitals with emergency departments. Inpatient cases were identified from this series and national estimates calculated.

Results

Between 1979 and 1992 there were 1,239 firearm related injuries in NZ, an average of 89 per year. The crude morbidity rate for the study period was 2.7 injuries per 100,000 population (95% CI: 2.6-2.9). The equivalent estimate for USA was 22.0 per 100,000 population (95% CI:13.0-31.0) (Table 1). In both countries male victims predominated.

The distribution of incidents shows that relative to USA a disproportionate part of the burden in NZ falls on the younger age groups. In both countries those in the 15-24 year age group have the highest rates of injury.

There were marked differences in the circumstances of injury. In the NZ series 64% of the injuries were considered to be due to unintentional events whereas they accounted for only 13% in the USA series with assault being the main contributor at 61%.

Similar marked differences were apparent with respect to type of firearm. In the USA inpatient series 35% of the incidents involved handguns, whereas in the NZ series, less than 2% involved handguns. Long guns (shotguns, and rifles) accounted for 45% of all NZ incidents.

Table 1 - Non Fatal Firearm Injuries NZ/USA

	% Distribution		Crude Rates*	
	NZ (1979-92)	USA (1992-93)	NZ (1979-92)	USA (1992-93)
Gender				
Males	90.6	87.7	5.0	39.6
Females	9.4	12.3	0.5	5.3
Age Group				
0-14	9.3	4.1	1.0	4.1
15-24	45.9	40.9	7.0	63.6
25-44	35.2	46.0	3.3	31.4
45-64	7.8	6.9	1.2	7.9
≥65	1.8	1.7	0.5	2.9
Event				
Unintentional	64.4	13.4	1.7	2.9
Self-inflicted	13.8	7.4	0.4	1.6
Assault	15.4	61.1	0.4	13.5
Legal intervent	-	1.2	-	0.3
Undetermined	6.1	16.9	0.2	3.7
Firearm				
Shotgun	25.1	7.0	0.7	1.5
Rifle	20.3	3.7	0.5	0.8
Handgun	1.6	35.2	-	7.7
Unspecified	53.0	54.2	1.4	11.9
Total	-	-	2.7	22.0

* per 100,000 pop'n

Discussion

The USA population rate was eight times that reported for NZ. One potential explanation for the difference is NZ's stricter laws regarding to the sales and possession of firearms and in particular handguns. Past and current law has restricted handgun ownership to bona-fide members of pistol clubs.

It is not immediately apparent why a relatively high proportion of young New Zealanders are involved in firearm incidents. The reason may related to New Zealand's relatively high youth an young adult participation levels in sporting activities and strong tradition in outdoor recreation activities which involve firearms (e.g. deer culling, pig shooting) (Reeder et al 1991).

The most dramatic difference between the two countries was in the inpatient injury rates for firearm assault (Table 1); the crude rate for USA was 34 times greater than that for NZ. One possible explanation may be that USA has higher overall levels of assault than Zealand. The absence of national USA inpatient data precludes a comparison of rates of serious assault between the two countries. USA had a 1992 homicide (all causes) rate of 10.0 per 100,000 population (Kochanek & Hudson 1994) whereas that for NZ was 2.5 (New Zealand Health Information Service 1994). While significant, this suggests that the difference in firearm assaults between the two countries cannot be entirely explained as a reflection of the differences in overall levels of assault.

The absence of detail on the specific type of firearm in over 50% of the cases in both series limits our ability to delineate the reasons for the differences between the countries. For example, given New Zealand's stricter handgun laws, victims unintentionally injured may suppress the fact that a handgun was involved. It is also of concern for both countries in that various strategies are in place or have been suggested for the control of specific types of firearms.

Most international comparisons of health statistics focus on mortality. This is because of the gravity of these events, relative reliability of the fatality statistics, and the absence of population based data on non-fatal outcomes in most countries. In that it utilises morbidity data in comparing two countries this study represents a significant advancement. Explanations for the marked differences in the circumstances of firearm injury probably lie in a combination of differences in firearm policy and more general socio-cultural factors. This needs to be investigated further through more detailed epidemiologic studies and international comparisons which include mortality, morbidity and risk factor data.

Acknowledgements

This research, was funded by the Health Research Council of New Zealand and the Accident Rehabilitation and Compensation Insurance Corporation.The injury data for New Zealand were provided by the New Zealand Health Information Service.The authors wish to thank Pam Jemmett, Dianne Allnatt, Judith Smeijers, and Jonathon Alsop for assisting in the preparation of this manuscript.

We would also like to thank Art McDonald, director, and Eileen Kessler, statistician and project officer, Division of Hazard and Injury Data Systems; and other staff of the USA Consumer Product Safety Commission for their diligence in providing high-quality surveillance data on nonfatal injuries using the National Electronic Injury Surveillance System. We also thank Steve James for programming assistance.

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A geometric extension to the Injury Severity Score (ISS) methodology for patients with 4 or more injuries.

Shai Linn, Head, Department of Epidemiology, Rappaport Faculty of Medicine, Technion-Institute of Technology, and Rambam Medical Center, Haifa, Israel.

ABSTRACT. One of the more-often used measures of multiple injuries is the Injury Severity Score (ISS) which is the sum of squares of the highest abbreviated Injury Scale values in each of the three most severely injured body regions. The ISS is neither a summary of injuries in all body regions nor a comprehensive summary of injuries in one body region. This paper suggests a geometric extension of the ISS to assess the overall severity of all injuries, the complete ISS (CISS). This measure is used to examine data on 761 patients injured during a war. CISS is used to predict LOS for patients with 4 or more injuries. CISS is compared to ISS in order to evaluate the importance of the new methodology in patients with four or more injuries.Contrary to the ISS, the CISS allows the consideration of several injuries in the same body region and the summing of an unlimited number of injuries in all body regions.

INTRODUCTION

The assessment of the overall severity of multiple injuries is fundamental for appropriate treatment and assessment ofmedical care. One of the most important and more-often used measures of multiple injuries is the Injury Severity Score (ISS), first proposed by Baker(1,2). Determination of the ISS is based on the Abbreviated Injury Scale (AIS)(1-9) which is a numerical scale of injury severity ranging from 1 (minor injury) to 6 (maximal injury-unsurvivable) (Table 1). Injuries are determined for each of the body regions (Table 2). The ISS is the sum of squares of the highest AIS values in each of the three most severely injured body regions (Table 3). Thus, it summarizes the anatomic trauma to one or more body regions and can provide a scalar description of the overall severity of injury in patients with multiple trauma.

While aimed at the overall description of severity, the ISS is not a comprehensive summary of injuries in all body regions and may underestimate the impact of all injuries to a person. The ISS describes the anatomical damage in the three most severely injured body regions but its shortcomings are well recognized (1,10,11). The inclusion of an AIS in the ISS calculations is relative to the AIS in other regions. The ISS can be an underestimate of the description of multiple severe injuries when four or more injuries occur, because only three of the injuries are considered.
In addition, the ISS is not a comprehensive summary of injuries in one body region (1,11). The ISS takes into account the most severe injury in three different body regions. However, when two or more injuries occur in one body region, the equally serious or less serious injury is not considered, although multiple serious injuries in the same body region are possible, particularly in penetrating abdominal or thoracic injuries. Examination of causes of mortality in 3000 casualties with penetrating abdominal injuries in World War II indicated that "case fatality rate increased about 15 percent as each additional viscus was injured" (12). In a more recent study, Bellamy and Vayer concluded that "assigning the same risk to a casualty with multiple organ injuries within one body region as to a casualty

with a single organ injury is manifestly unreasonable"(13).

This paper suggests a new approach to assessing the overall severity of injury and explores ways to describe fully four or more injuries. CISS is used to predict LOS for patients with 4 or more injuries. The findings are compared to the ISS in order to evaluate the importance of the new methodology.

Geometric analogy.

The ISS is calculated as the sum of squares of the AIS in each of the three most severely injured body regions.

1. $ISS = AIS_1^2 + AIS_2^2 + AIS_3^2$

An equation similar to the Pythagorean triangle theorem will be used to enable all injuries to be considered. Conceptually the sum of the squares of all AISs along the right angle sides are considered to equal the square of the hypotenuse (r_i) which is considered to be the magnitude of the severity (Figure 1):

2. $r_2^2 = AIS_1^2 + AIS_2^2$

3. $r_3^2 = r_2^2 + AIS_3^2 = ISS$

Conceptually, one could continue analogous calculations to include additional AISi for each injury (i) in all body organs that are affected, without being limited to only three injuries in different organs.

Similar to the ISS, a complete ISS (CISS) for i injuries can now be defined:

4. $CISS_i = r_i^2 = \Sigma AIS_i^2$

The length of final vector is, in fact, an overall description of the magnitude of severity, taking into account all injuries to a person.

EXAMPLE: The medical records of all patients admitted to the Emergency Department of Rambam Medical Center (RMC) during the war in Lebanon from June 6-30, 1982, were reviewed.All data, including medical characteristics, were recorded, using a detailed coded questionnaire(14).All 780 casualties were included in this study. Five patients who had an AIS of 6 were excluded from the analyses because the comparison of their ISS (assigned to be 75 per definition) and the CISS was not meaningful. For 14 patients who were hospitalized for reasons other than trauma, an ISS could not be determined and they were also excluded from the analyses, leaving a total of 761 patients to be considered. Four physicians independently examined each medical record and coded questionnaire to determine the ISS. This team was not aware of the planned study to compare ISS and CISS. The 1985 AIS revision was used to determine the AIS score and then to calculate the ISS(7, 14). In cases of disagreement, the ISS value was determined by consensus.

STATISTICAL ANALYSES

The analyses explored the differences between ISS and CISS for individuals with different numbers of injuries. The ISS is a measure on an ordinal scale so that appropriate statistics for ordinal measures should be used in statistical analyses (1, 10, 16). Thus, the medians are examined here to get more insight into the CISS methodology.

The statistics were calculated using SPSS TABLES, and Wilcoxon's signed-matched test was used to test the hypothesis of no difference between the medians of the ISS and CISS.

RESULTS

The data demonstrate the relationships between the number of injuries and the magnitude of the injury severity score (ISS) or the complete ISS (CISS) (Table 4). A majority of the patients had three or fewer injuries. For them, the ISS and the CISS are identical, because both measures are based on the same most severe injuries when there are no more than three injuries.

Clearly, the CISS is higher than the ISS when all injuries are considered for those individuals who had FOUR injuries or more. The median CISS is higher than the median ISS by 4.8%, 16% and 9.1% for individuals with 4, 5 and 6 injuries, respectively. Wilcoxon's signed-matched test indicated statistically significant differences between the scores of those individuals with 4 and 5 injuries. Considering all 44 patients who had 4 or more injuries yielded similar findings: the median ISS was 22.0, while the median CISS was 23.0, also a statistically significant difference.

When the ISS and CISS were compared for all 761 patients, the differences were statistically significant. Thus, CISS is important also in the assessment of injury severity of a population with mixed patterns of injuries of various severity levels.

DISCUSSION

The CISS is informative and different from the ISS only when an individual has four or more injuries, and the magnitude of the difference is a function of the severity of the fourth and more injuries. Clearly, CISS is always bigger than ISS because it takes into consideration more AISs. In most patients, the additional AISs that are included in the CISS calculation have a smaller magnitude than those which are included in the ISS, because the ISS considers the three most serious AISs. Therefore, CISS calculations can be especially useful when four of more severe injuries occur. Even when the ISS serves as a measure of injury severity, the comparison of CISS and ISS is suggested in order to indicate whether there is bias because of unaccounted injuries in the ISS. When such bias exists, the CISS could be used in addition to the ISS. This would be appropriate as an analysis tool when the examined population includes many patients with 4 or more severe injuries.

An AIS 6 (unsurvivable) is an exception to all other AISs because it automatically leads to an ISS of 75. Thus, the ISS calculations depend on a single injury. I suggest adhering to this convention, in order to enable comparability to the ISS. However, the CISS should be used when 4 or more injuries are considered and would not be useful in cases with an AIS 6.

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Table 1

Description of the Abbreviated Injury Severity Scale (AIS)

AIS =1 : MINOR
AIS =2 : MODERATE
AIS =3 : SERIOUS BUT NOT LIFE THREATENING
AIS =4 : SEVERER, LIFE THREATENING, SURVIVAL PROBABLE
AIS =5 : CRITICAL, SURVIVAL UNCERTAIN
AIS =6 : VIRTUALLY UNSURVIVABLE

Table 2
Body regions for AIS Classification

1990 revision
1- Head
2- Face
3- Neck
4- Thorax
5- Abdomen & pelvic contents
6- Spine
7- Upper Extremities
8- Lower Extremities
9- Unspecified
Note: External injuries have been dispersed across body regions.

Table 3

Body regions for ISS calculations

1- Head or neck
2- face
3- Thorax
4- Abdomen
5- Extremities
6- External

$$ISS = AIS_1^2 + AIS_2^2 + AIS_3^2$$

Note:

1) The ISS body regions do not coincide with the sections used in the AIS.

2) The ISS calculations included head or neck in one region and face in a different ISS region.

3) The ISS calculations included spine injuries into the corresponding three ISS body regions: cervical in ISS Head or Neck, thoracic in ISS Chest and lumbar in ISS Abdominal or Pelvic Contents.

Table 4

The relationships between ISS, CISS and the number of injuries. Median ISS and CISS

Total of injuries	1	2	3	4	5	6
N	440	197	80	33	10	1
ISS	4	10	14	21	25.66	
CISS	4	10	14	22	29	72
Wilcoxon's p <0.01				*	*	

□

ACKNOWLEDGEMENT

This study was supported by the Social Science Research Council- MacArthur Foundation, 605 Third Avenue, New York, N.Y., 10158, the Israel Ministry of Defense and the Bureau of Rehabilitation.

The author wishes to thank Mrs. M. Perlmutter for her assistance in preparing this manuscript.

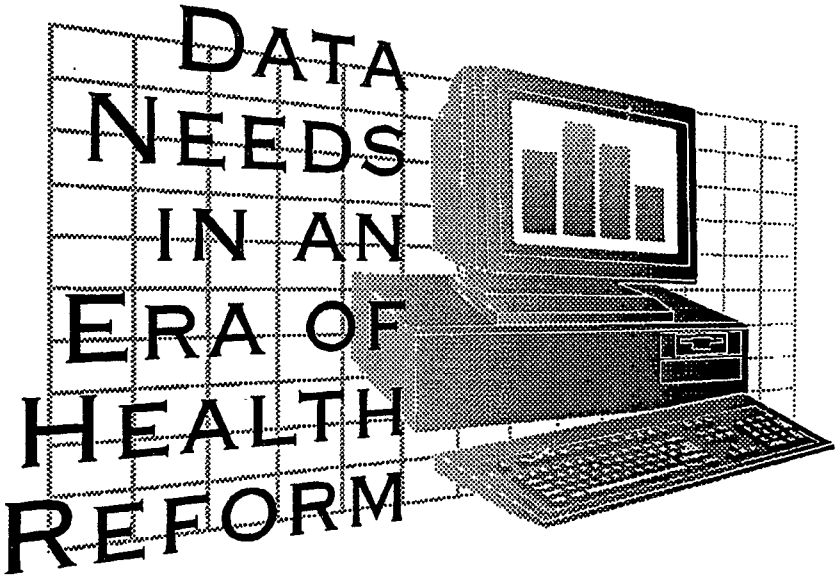
INTERNATIONAL REPORTING OF INJURIES
Discussant

Cleone Rooney, Office of Population Censuses and Statistics

Comments not available for publication.

Session F

Public Health Applications using Geographic Information Systems



SURVEILLANCE OF CHILD PEDESTRIAN INJURIES: A GIS APPROACH

Ellen K. Cromley, University of Connecticut
Garry M. Lapidus

The research presented here demonstrates the usefulness of geographic information systems (GIS) technology for monitoring childhood injury arising from motor vehicle collisions with child pedestrians. Developed under the auspices of the Connecticut Childhood Injury Prevention Center based at Hartford Hospital and supported by the Hartford Foundation for Public Giving and the University of Connecticut Research Foundation, this GIS application helped the Center to determine whether and how many high frequency collision sites exist in the Town of Hartford and what the key attributes of collision occurring at those sites are. The databases compiled for the project and the GIS functions used to analyze the data are outlined. The implications of the research for designing public health intervention programs to reduce childhood injury are considered, along with several more general conclusions about the role of GIS in public health.

Child pedestrian injury is a public health problem of national and local importance. According to the Center for Environmental Health and Injury Control of the Centers for Disease Control and Prevention, pedestrian injuries are a significant cause of death for all children from 0 to 19 (Center for Environmental Health and Injury Control 1990, 11). Nonfatal pedestrian injuries are common among 5 to 9-year-old children, particularly males. An estimated 51,000 child pedestrian injuries occurred in the U.S. in 1985, resulting in hospital admission of 18,000 children.

The geography of motor vehicle-related deaths is captured in the Injury Mortality Atlas of the United States, 1979-1987 (Center for Environmental Health and Injury Control 1991, 29-30). Although most of these deaths occurred among vehicle occupants, pedestrians account for about 15 percent of the deaths. This common view of the geography of health problems (a map of rates calculated for county aggregates displayed with a quantile classification scheme) suggests that motor vehicle-related death rates are lower on average in the northeastern United States. At the local scale, however, we find that motor vehicle-child pedestrian injury is the leading cause of injury death in the Town of Hartford and the second cause of injury hospitalization (Lapidus and Banco 1990). Recognition of this problem prompted development of a GIS application for childhood pedestrian injury surveillance.

Geographic information systems are automated systems for collecting, storing, analyzing, and displaying spatially-referenced data (Department of the Environment 1987, 132). For the surveillance application, several geographic and thematic databases were compiled. The geographic databases for the project included an address-ranged street network database for the Town of Hartford and a database of 1990 census tract boundaries, both extracted from the 1990 Census version TIGER/Line Files for Hartford County (U.S. Department of Commerce, Bureau of the Census 1991).

The thematic databases included road class and average daily traffic count data provided by the Connecticut Department of Transportation, 1990 child population by census tract from the 1990 Census of Population and Housing (U.S. Department of Commerce, Bureau of the Census 1992), and a database of information from Police Accident Reports for all motor vehicle collisions from January, 1988, through December, 1990, occurring in the Town of Hartford and involving pedestrians less than 20 years of age. These reports are presumed to include all serious injuries to children but may underrepresent minor injuries. The State Department of Transportation compiles these reports for all police units in the state and provided a printout of all cases.

The PAR database for the study period included information on 359 collisions spread almost evenly over the three-year study period and involving 382 vehicles and 374 child pedestrians. The following information was extracted from each report: case number, date and time of collision, collision location, injury severity, environmental conditions (weather, light, and road surface), vehicle type, pedestrian/driver maneuvers, contributing factors, pedestrian/driver demographics (age, sex, and place of residence), and driver/pedestrian use of alcohol or drugs. Driver data were missing for about 16% of drivers who left the collision scene.

Injury severity is an obvious factor to be considered in targeting locations for public health interventions. Analysis of the other variables ties the injury to the three main prevention strategies available--education, enforcement, and environmental modification--and research on their effectiveness.

The specific GIS functions used in the application included compilation of the geographic databases, geocoding collision sites and driver and child pedestrian residences, cartographic display, selecting objects based on geographic/thematic attributes, and distance measurement. The geography of motor vehicle hazard is represented by the street network for the Town. We can modify this view to represent segments of the street network where the volume and speed of traffic are high by selecting those segments of the street network having the specified attributes (Figure 1). In this view, we see the locations of the Interstate Highways and the principal and minor arterials.

The residential geography of children in the Town of Hartford is represented by the census tract distribution of the child population. The 12 highlighted tracts in this view (Figure 2) account for 45% of the population under 20, each tract having a population of at least 1250 people in this age group.

The locations of motor vehicle-child pedestrian collisions, driver residences, and child residences were geocoded using a commercial GIS software package (Caliper Corporation 1990). The cartographic display function was used to generate point maps of collision locations against the distribution of child population and against the street network (Figure 3).

Studies of collision clustering generally delimit linear segments of fixed length in the street network where more than a specified number of collisions have occurred over a fixed time period. An examination of the geographical distribution of collision sites here uncovered a number of high occurrence areas that could be identified using this approach (Figure 4). One cluster occurs along a one-mile stretch of Albany Avenue (federal route 44 and a principal arterial) where 24 children were involved in 23 collisions over the three-year study period. A second type of "cluster" is apparent in occurrences on groups of adjacent streets having similar land-use characteristics. An example of this type of cluster occurs in the Park Street neighborhood where the collection of streets features a very mixed commercial/residential land use pattern on Park and Broad (minor arterials) and their connectors. This network of street segments, running 0.8 mile east-west and 0.3 mile north-south accounted for 38 collisions involving 38 children over the three-year study period. Together, the two locales accounted for 17% of all collisions, and were selected to illustrate the type of analysis carried out in the larger research project (Braddock, et al. 1994).

Once the high collision locales were identified, a profile of each collision site was prepared based on the attributes of the collisions and the children and drivers involved. Again, the cartographic display functions of the GIS were useful for exploring differences between the two sites. An important variable for these two locales is the age of the child pedestrians (Figure 5). The average age of child pedestrians struck on Albany Avenue was 12 (only 25% less than or equal to 7 years of age) while the average age in Park Street was 8 (61% less than or equal to 7 years of age).

Relationships between child and driver residences and the collision site are also important for intervention strategy development. The map of the residential locations of children involved in collisions looks rather similar to the map displaying the distribution of collision sites. This does not necessarily mean that children are being hit by cars in their own neighborhoods. Distance from child and driver residence to the collision site were calculated using the GIS. In the Albany Avenue case, for example, children are apparently farther away from home when the collision occurs than they are in the Park Street case. This finding is, perhaps, not surprising given the age differences between the two groups of children. In Park Street, however, the children are often hit in front of their own homes and it is possible that the difference in distance to residence represents different uses of street space: as corridors for movement in the Albany Avenue case or as activity space in the Park Street neighborhood case.

The Albany Avenue collisions were more likely than collisions at other sites to occur during the spring, in the middle of the afternoon (around school dismissal time), on a weekday, at an intersection, and to involve older children. The Park Street collisions, though resulting in less severe injuries, were numerous and were more likely to occur around the evening rush hour involving passenger cars that were driving straight at the time of the collision with a young child. A site-specific intervention program suitable for Albany Avenue might include education programs for school-aged children; improved enforcement of vehicle speed laws and adherence to traffic signs; and environmental modifications to improve intersection crossing times and increase child pedestrian visibility. In the Park Street area, education efforts directed at parents of preschoolers and young school-aged children, increased use of warning signs, and the development of

off-street playground areas might be effective prevention strategies.

Several important conclusions can be drawn from our experience using GIS to study the public health problem of child pedestrian injury. The GIS analysis enabled us to identify high occurrence locales, to explore the attributes of the collisions occurring there, and to develop site-specific intervention strategies. The knowledge gained from this project has enabled the Connecticut Childhood Injury Prevention Center to work with local groups to design and implement intervention strategies at a number of the high collision locales we identified (Shanahan 1995).

Depending on the nature of the process being studied, "clusters" of health problems can have very different geometries (circular or linear). The underlying spatial structure of the street network or residential development in an area which can be represented effectively with GIS provides an important context for cluster identification. The GIS aided in the delineation of substantively meaningful clusters.

This application also highlights the importance of recognizing that the home location is only one site (though an important one) where human populations can be exposed to health hazards. Mapping health problems by residential location may not always be appropriate if the home is not where exposure is occurring. In this application, we were able to represent multiple locations relevant to the health problem. Related to this point, we realized the ability of GIS to integrate databases from many different sources.

The Injury Mortality Atlas provides a series of maps depicting the county-level distribution of injury mortality rates for various types of injury for the individual states. Based on this traditional approach to the geography of health problems, the maps for Connecticut (Center for Environmental Health and Injury Control 1991, 48) depict almost no geographical variation in injury mortality rates across the state. The application of GIS technology, on the other hand, uncovers the rich and complex geography--worthy of investigation--that underlies public health problems like child pedestrian injury. The development of GIS is providing us with a powerful new force in the conceptual and methodological armamentarium of public health.

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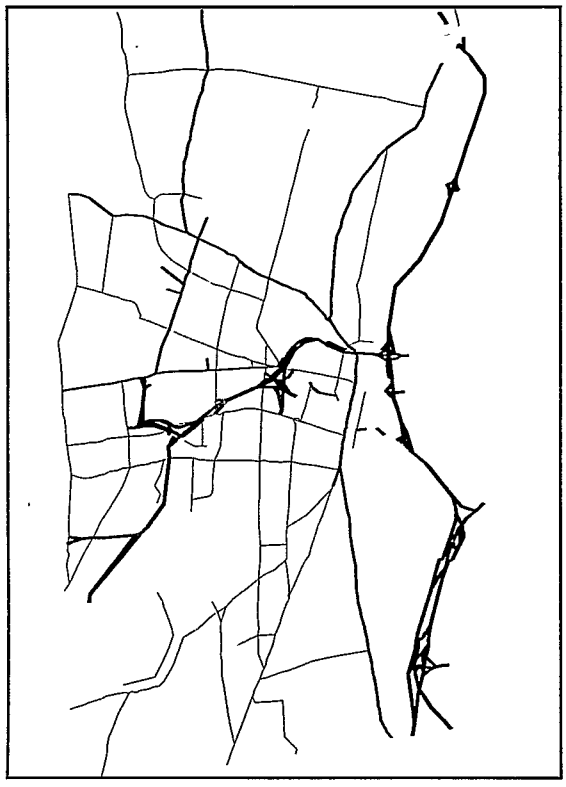


Figure 1. Interstates, principal and minor arterials in the street network.

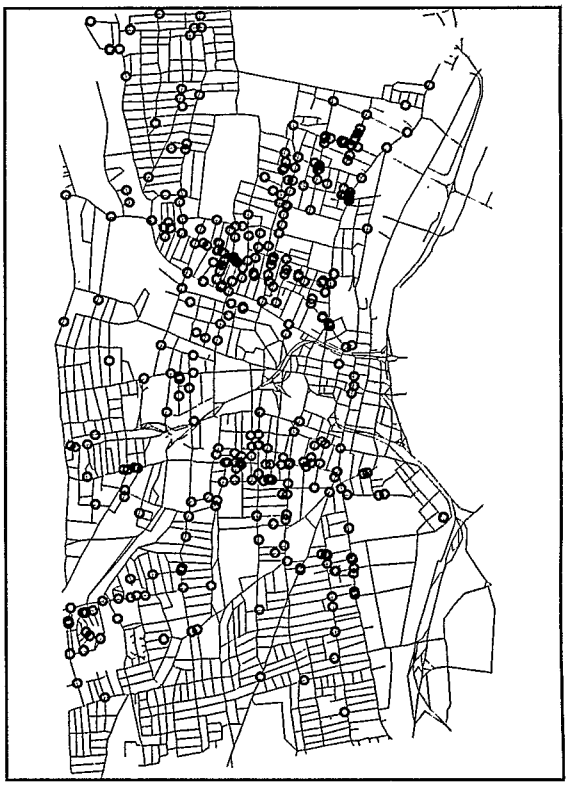


Figure 3. Child pedestrian collision sites, 1988 through 1990.

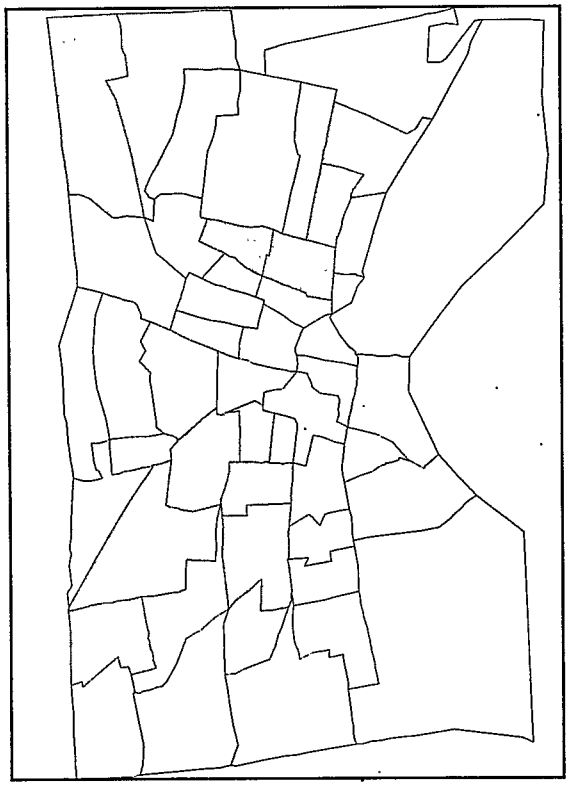


Figure 2. Census tracts where child population exceeded 1,250 in 1990.

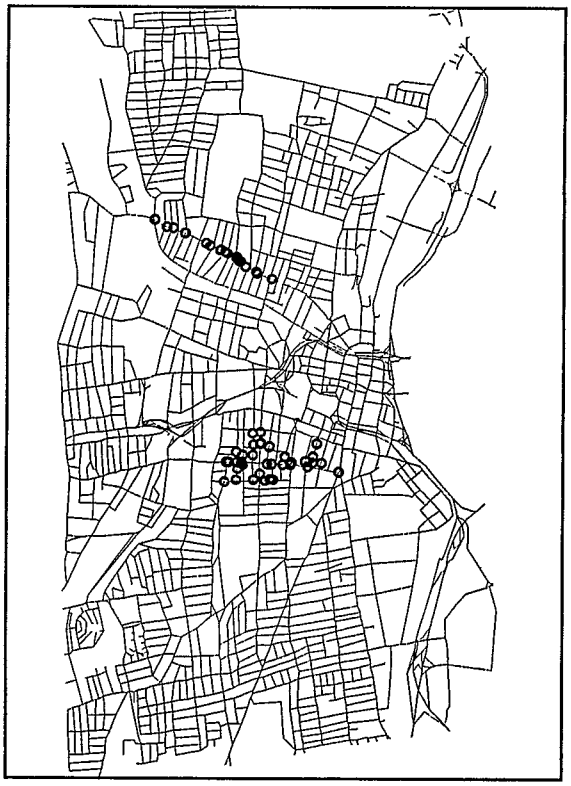


Figure 4. Collision clusters along Albany Avenue and in Park Street neighborhood.

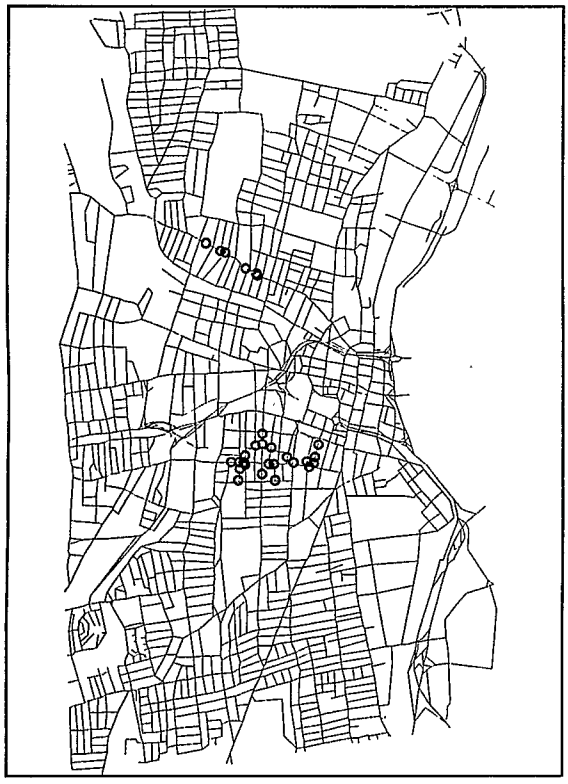


Figure 5. Locations of collisions occurring in the clusters and involving children 7 years or younger.

SPATIAL AND TEMPORAL TRENDS IN LOW BIRTHWEIGHT: A GIS ANALYSIS

Sara McLafferty, Hunter College

Paper not available for publication.

RISKS FOR CONGENITAL MALFORMATIONS ASSOCIATED WITH PROXIMITY TO TOXIC WASTE SITES

Sandra A. Geschwind, RAND

Paper was not presented.

SPATIAL ANALYSIS OF INFANT MORTALITY RATES IN DES MOINES, IOWA, 1989-1992

Gerard Rushton, The University of Iowa
Diane Krishnamurthi
Rajesh Krishnamurthy
Hu Song

Summary

The spatial pattern of infant mortality in the Des Moines, Iowa, urban region is described as a contoured surface based on the application of a spatial filter to address-matched, vital statistics records from The Iowa Department of Public Health. Areas defined as having high rates are shown to be sensitive to the size of the spatial filtering units. The significance of areas with high rates is determined by a Monte Carlo simulation procedure.

1. Methodology

We view infant mortality rates as varying continuously throughout any urban area. Taking any location at random, we can define its infant mortality rate by selecting an arbitrarily sized region surrounding it of a size sufficient to capture enough observations of births and deaths to estimate, reliably, the rate. If we repeat this for a grid of such estimates, we can interpolate the infant mortality rate as a continuous spatial distribution. From each, location on a square grid with locations approximately 0.4 miles apart, a circle of 0.4 mile radius is drawn and the number of births and infant deaths within the circle area is computed. The infant mortality rate is defined for the grid location at the center of each circular area as the ratio of infant deaths to births found in the area for the time period specified. This method, known as "punctual kriging" is used widely in the geo-sciences (Carrat and Valleron, 1992; Webster et al., 1994; Oliver et al., 1989). A continuous spatial distribution of infant mortality rates is computed by a contouring procedure which interpolates contours of equal rate values from the rates computed at the grid locations (Openshaw et al., 1987; Openshaw et al., 1988; Turnbull et al., 1990).

2. Application

This methodology is illustrated in Figures one through ten. In Figure 1 we show the spatial pattern of infant deaths in the central part of the Des Moines metropolitan area from 1989 through 1992--the most recent years for which disease registry data is available. Of the 209 infant deaths in this region in this four year period, 192 were successfully address-matched (Geographic Data Technology, 1993; U.S. Bureau of the Census, 1993). Their locations are shown with their locations (latitude, longitude coordinates) randomly distorted according to a uniform distribution within an approximate 0.5 mile radius. This random distortion of observed locations preserves the essential features of the pattern, but also preserves the confidentiality of the personal information, which is an absolute priority in studies of disease distribution, since the rights of individuals to privacy must be assured.

For the inset area in Figure 1, the spatial distributions of infant deaths and births are shown in Figures 2 and 3. The density of births in this region demonstrates that the pattern of births for the entire metropolitan area would be obscured if mapped as a dot density map at the scale of Figure 1. Figure 4 illustrates the spatial pattern of grid points for the area of Figure 1.

The spatial filter area surrounding each of these points is the area from which an estimate of the infant mortality rate is made. In this case, the spatial filter area is defined as within a 0.4 mile radius from each grid point and the grid points themselves are approximately 0.4 miles apart. Figure 5 shows the interpolated infant mortality rate values. For this area there were at least 40 births in each filter area between 1989 and 1992. On this map, many small areas throughout the area have infant mortality rates in excess of 20 per thousand live births (compared with 9.5 per thousand for the County-wide rate).

Details of the spatial pattern of infant mortality are sensitive to the size of the spatial filter. In Figures 6 and 7 we demonstrate how increasing the size of the filter from 0.4 to 0.8 and 1.2 mile radius for the same grid points as in Figure 5, results in a spatial pattern with fewer local high and low rates in the larger region. Locally high rates, because they are based on smaller numbers of births and deaths, are likely to be more variable than regionally smoothed rates which are more likely to reflect the region-wide average rates. In the spatial statistics literature, the spatial filter is generally referred to as "the spatial operator". Thus we see in this case that as the size of the spatial operator increases, the numbers of areas with larger than normal rates of infant mortality are fewer.

3. Significance of Observed Rates

Tests for significance of these rates were made using methods described in Rushton and Lolonis (1995). We assume that the probability a birth in the area becomes an infant death is equal to the proportion of all births in the region that resulted in infant deaths. A Monte Carlo simulation is used to determine whether each birth location in the 1989-92 period resulted in an infant death. One thousand such simulations, resulting in 1,000 synthetic maps each of which was examined using the spatial grid and spatial filter process described above. For each grid point, therefore, 1,001 infant mortality rates existed--the first rate is the observed rate and the remaining 1,000 rates are the simulated rates. For each grid location, the proportion of the simulated rates that were less than the observed rate was computed. This proportion is shown as a continuously distributed variable in Figure 8 for infant mortality rates. The largest area with significantly high infant mortality rates (Figure 8) is in the central part of the city of Des Moines where a large area exists in which more than 75 percent of the simulated infant mortality rates were less than the observed rate.

Figure 1: Infant Deaths, Des Moines, Iowa, 1989-1992

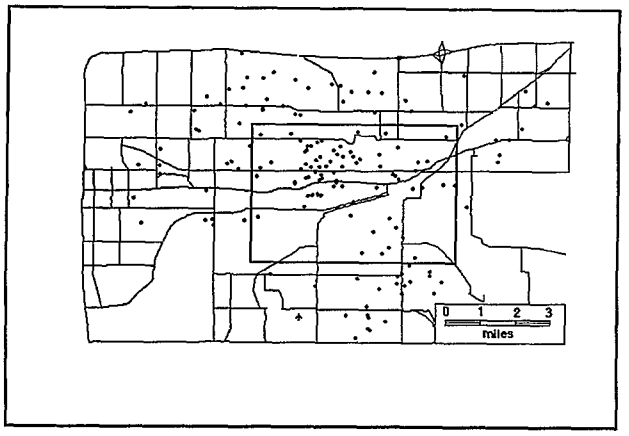


Figure 2: Infant Deaths in the Inset Region of Figure 1

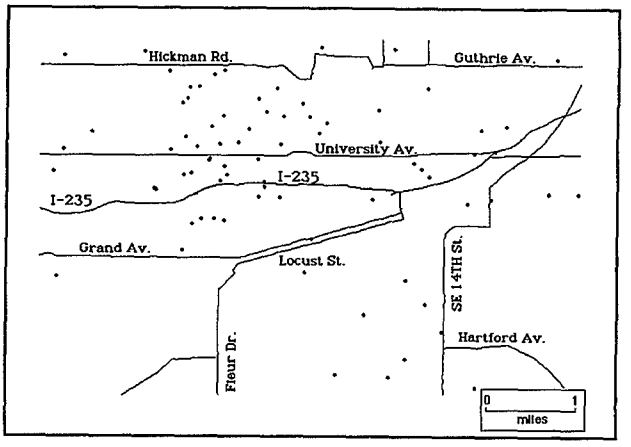


Figure 3: Births in the Inset Region of Figure 1

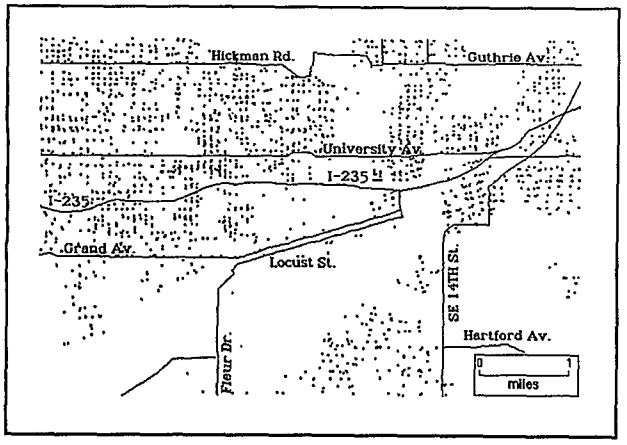
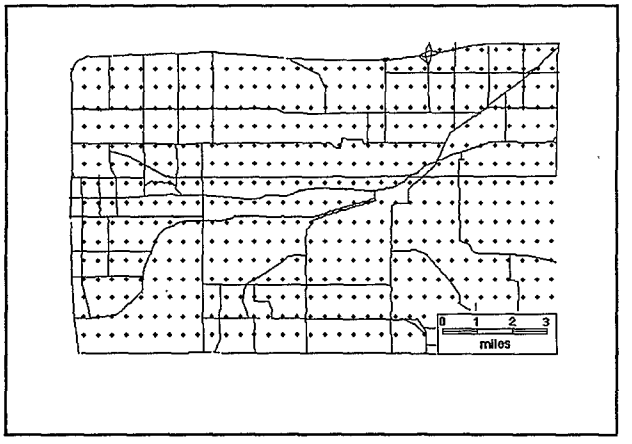


Figure 4: The Grid Locations for Which Infant Mortality Rates are Computed



4. Conclusions

Rates of infant mortality rates within the Des Moines urban region vary markedly within the region. The location and extent of high rates is strongly related to the size of the spatial filter used to measure them. Large spatial filters show few areas with high rates. Smaller filters show more, smaller areas, with high rates. The significance of areas with high rates was determined by Monte Carlo simulations which identified one, fairly large area, as significant.

Future work will attempt to control for known risk factors in infant mortality. With respect to rates of infant mortality we will adjust for stillbirths, neonatal and perinatal death rates, as well as known risk factors such as birth weight, prematurity, congenital anomalies, maternal age, prenatal care and race. Analyses that incorporate these factors must be completed before geographically-based intervention policies to improve outcomes can be determined. The Monte Carlo simulation process, by focussing on the locations of individual births, can use probability rates for each birth location that reflect the known covariates of infant mortality for a birth with the given characteristics.

Could this same conclusion have been reached by using traditional sources (U.S. Department of Health and Human Services, 1994) or by following the traditional approach to mapping infant mortality rates at the level of the census tract? Conference participants can judge this by reviewing Figures 9 and 10 and comparing the census tract based patterns of Figure 9 with Figures 5 and 8. This comparison shows that most of the census tract boundaries do not coincide with the regions of high infant mortality rates. This is clear and persuasive evidence that mapping health data into pre-defined census-defined areas,-- or any other exclusively defined area units-- will often conceal spatial patterns that can be better discovered by more flexible tools of geographic information analysis. Such exploratory spatial data analysis methods are useful for monitoring the health of small areas and defined population groups (Fotheringham and Rogerson, 1994). The approach has its place alongside the more traditional statistical techniques of confirmatory analysis which are usually used for studies of suspected disease clusters (see, for example, U.S. Department of Health and Human Services, 1990; American Journal of Epidemiology, 1990).

With support from the U.S. Department of Education, we are currently developing a CD-ROM which will provide instructional modules on the implementation of these methods as well as other applications of GIS and Public Health.

Figure 5: Infant Mortality Rates Defined by 0.4 Mile Filter, Des Moines, 1989-92

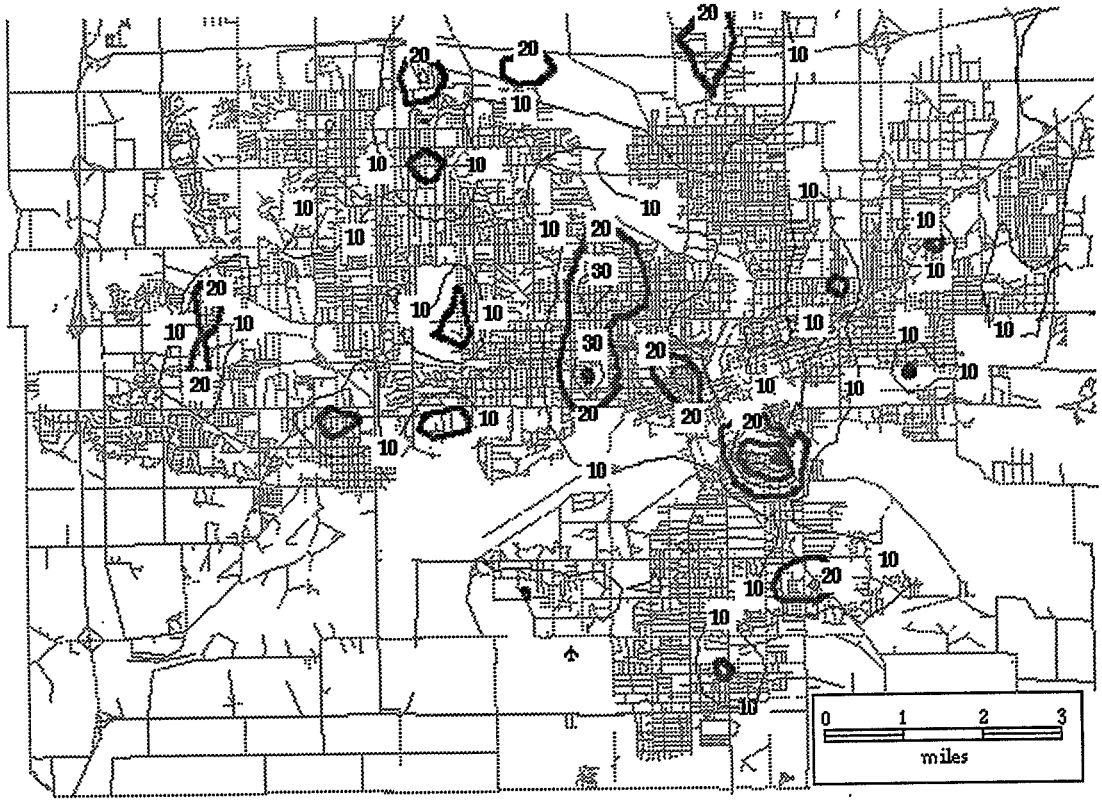


Figure 6: Infant Mortality Rates Defined by 0.8 Mile Filter, Des Moines, 1989-92

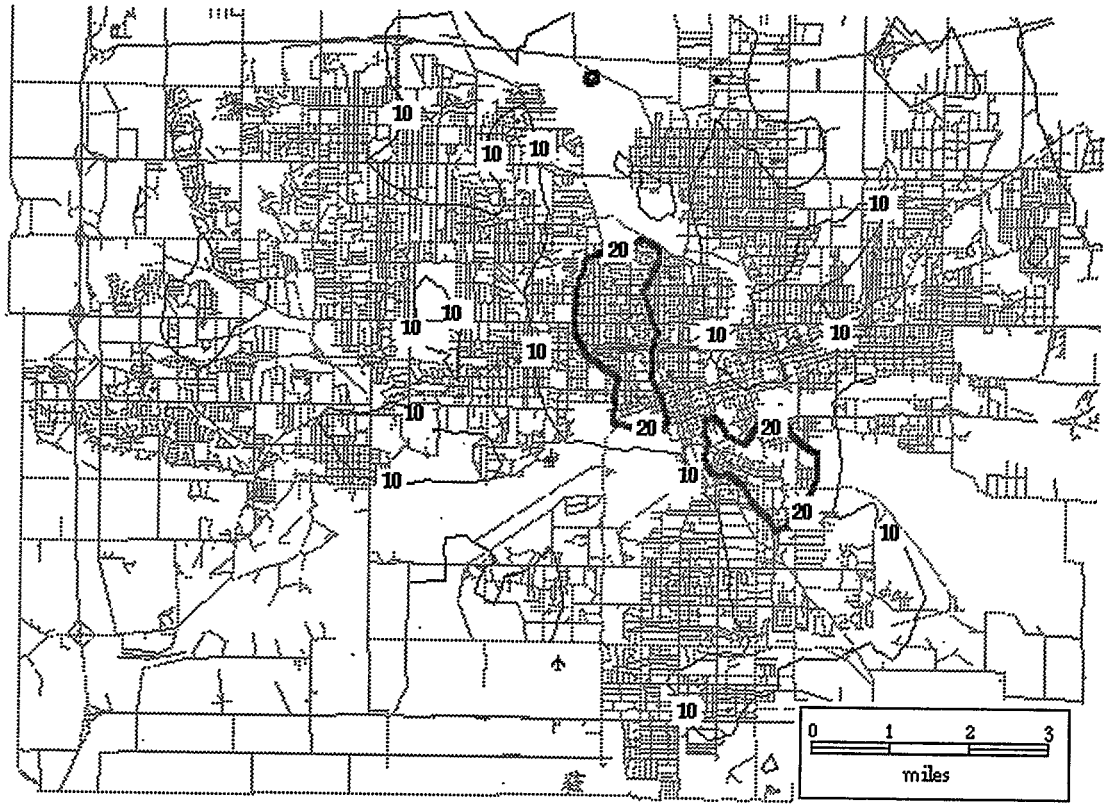


Figure 7: Infant Mortality Rates Defined by 1.2 Mile Filter, Des Moines, 1989-92

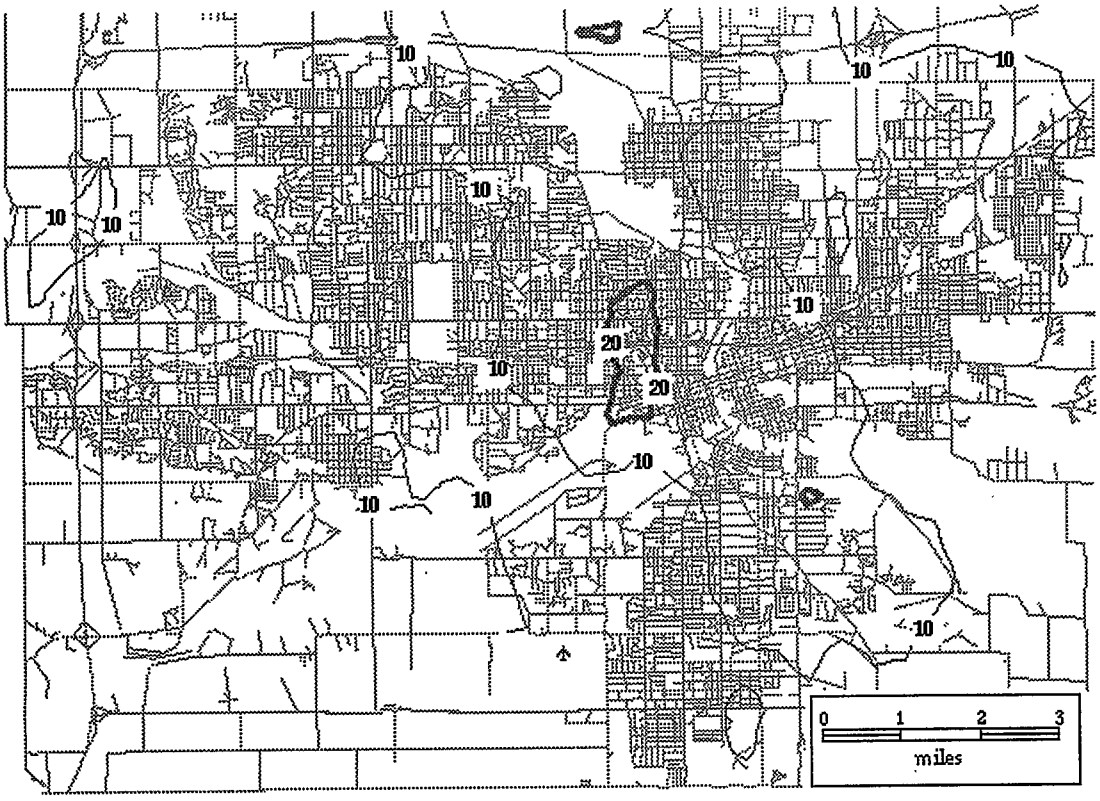


Figure 8: Significance of Infant Mortality Rates--Defined by Monte Carlo Simulation--Des Moines, 1989-92

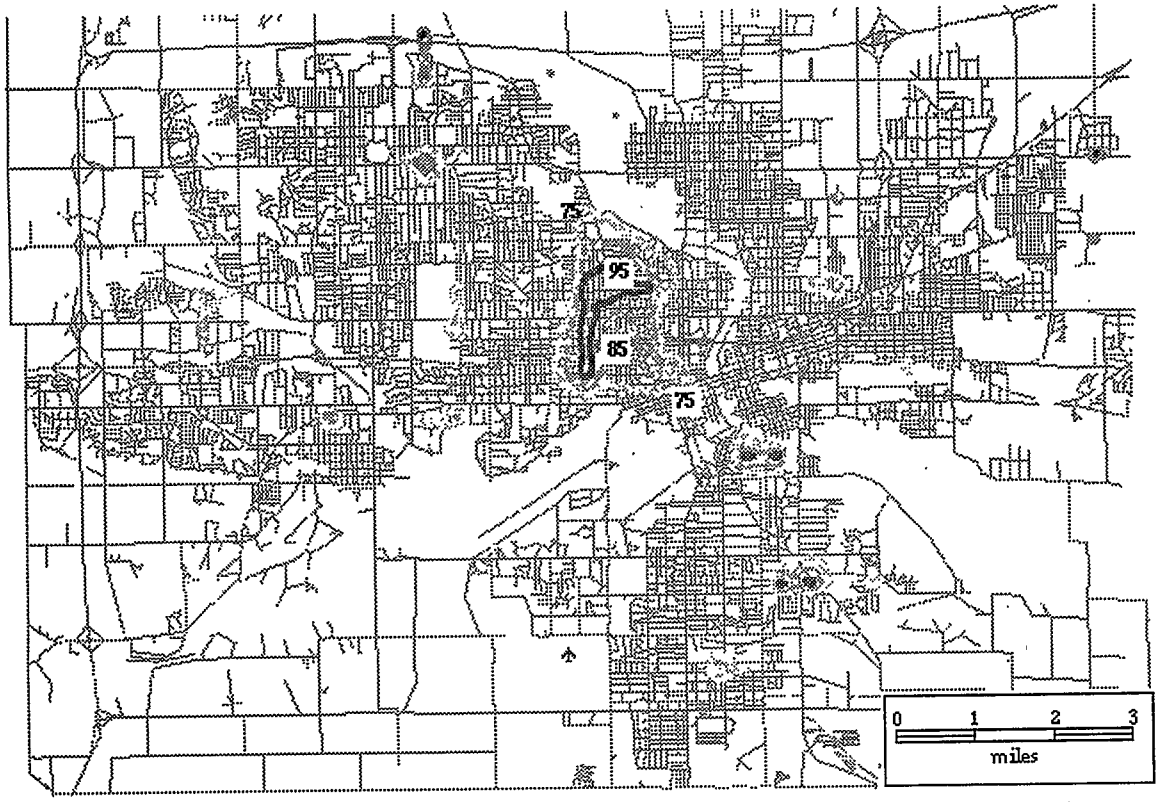


Figure 9: Infant Mortality Rates for Census Tracts, Des Moines, 1989-92

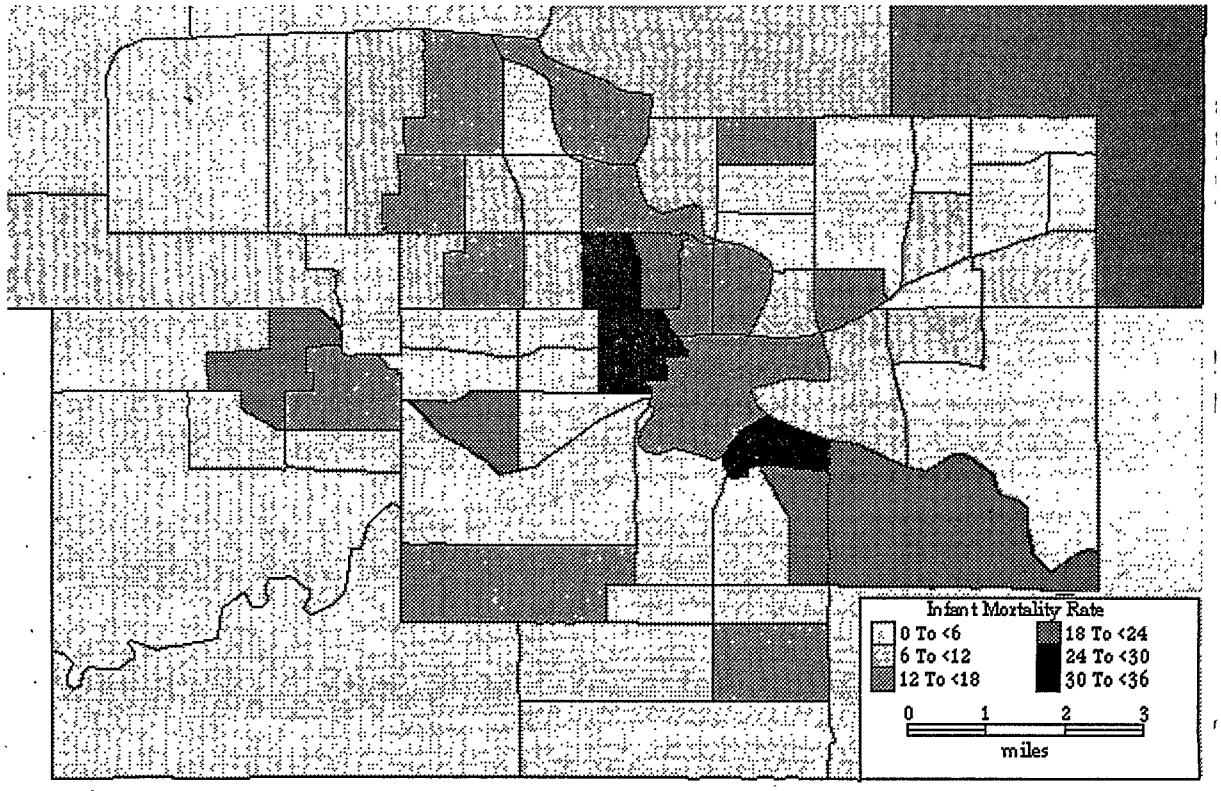
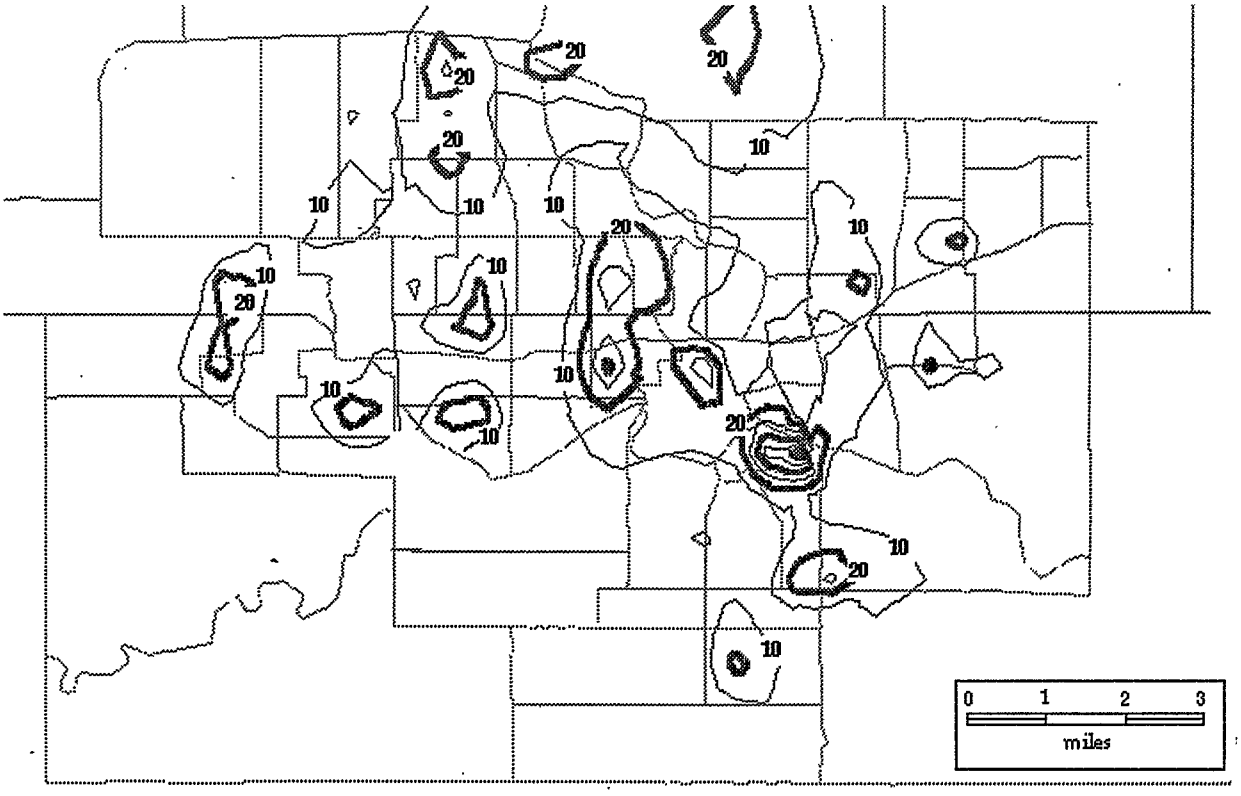


Figure 10: Spatial Overlay of Census Tract Boundaries and Infant Mortality Rates



Acknowledgments

We thank William Budelier, Charles E. Danielson, James Hanson, Muin Khoury, Kenneth Koehler, Marc P. Armstrong, Panos Lolonis, Allen Ibaugh, Amy Ruggles, James C. Torner, Dale Zimmerman and members of the Maternal and Child Health Review Committee of the Iowa State Department of Health for their assistance in this study. We also acknowledge a FIPSE grant from the U.S. Department of Education to develop instructional modules in GIS and Public Health, and assistance from Caliper Corporation, Newton, MA. and Geographic Data Technology, Inc., Lyme, NH.

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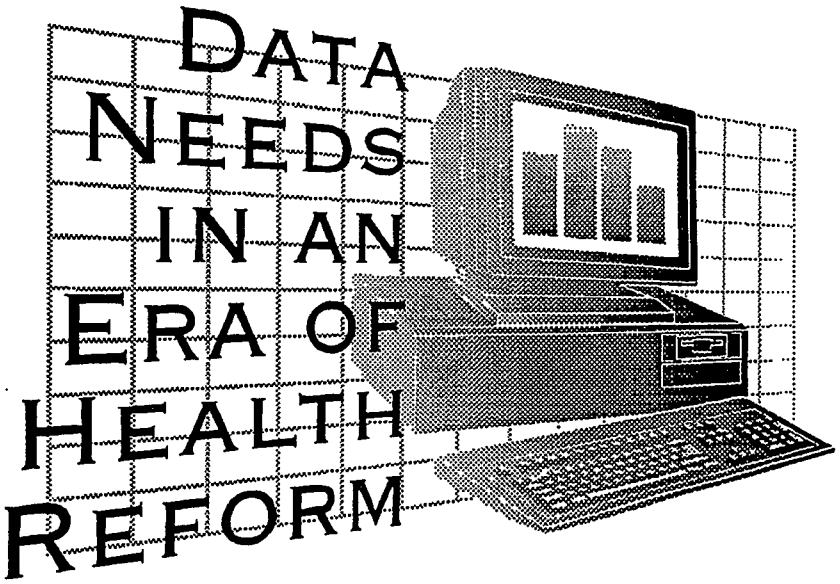
Session G

Emergent Care



DETERMINING WHO NEEDS THE EMERGENCY DEPARTMENT

Robert A. Lowe, University of Pennsylvania
Andrew B. Bindman
Susan K. Ulrich
Thomas A. Scaletta
Kevin Grumbach

There are 90 million emergency department (ED) visits a year in the United States (1), constituting approximately 3% of US health care costs, with an estimated $15 billion going to emergency department care in 1987. (2) Because charges for care in the ED are often greater than charges for similar care delivered in traditional primary care settings, the increase in utilization of EDs has generated substantial concern. Therefore a movement is underway to decrease inappropriate ED visits. This movement stems from two motivations: the concern for cost containment and the hypothetical potential for improving patient outcomes if channeling patients with minor problems away from the ED to traditional primary care providers can enhance continuity of care.

However, implicit in this movement is the assumption that the phrase "inappropriate emergency department visit" represents a valid concept and that reliable measures exist to ascertain the "appropriateness" of an ED visit. That this assumption may be problematic is illustrated by a common clinical scenario. Imagine a 60 year-old man who develops chest pain. There is nothing that a reasonable lay person can be expected to know or do to distinguish the pain of a life-threatening myocardial infarction from a trivial cause of chest pain. Therefore, it is reasonable to expect this patient to seek care in an ED. In the ED his first contact will be with the triage nurse, who briefly questions the patient about his symptoms and obtains vital signs. With this limited information, the triage nurse cannot confidently rule out a life-threatening cause for the patient's chest pain. Then, the patient sees an emergency physician, who obtains a more detailed history and performs a careful physical examination. The physician will almost certainly order an electrocardiogram and possibly other diagnostic tests. Let us suppose that after this evaluation the emergency physician concludes that the patient has gastroesophageal reflux (heartburn). Heartburn is clearly not life-threatening, and the patient is reassured and discharged home. In retrospect one can argue that the patient's ED care did not improve his health, so the ED visit was not appropriate. However "appropriateness," in this sense, could not have been ascertained prospectively, prior to a complete evaluation by the emergency physician.

Because of the problem in measuring appropriateness illustrated by this clinical scenario, we sought to ascertain whether different measures of appropriate ED use agree. The setting for the study was the San Francisco General Hospital (SFGH) ED, a high-volume inner-city ED with about 78,000 patient visits a year. Patients waiting for emergency care at SFGH during the week of July 9, 1990 were eligible for inclusion. Patients who could not be interviewed were excluded, including those younger than age 18, those who did not speak English, Spanish or Cantonese, and those who were not mentally coherent. Also excluded were those patients so ill that they were taken immediately to a resuscitation area. Finally, patients who left the ED prior to a complete evaluation were excluded, leaving 596 patients for the study. (Not all data were available on all patients.)

Seven measures of appropriateness were utilized for the study. Two were obtained from a questionnaire administered to patients in the ED waiting room. Patients were asked, "Sometimes people have to wait several hours in the emergency room. Instead of waiting now, would you prefer to have a doctor's appointment at a definite time in one to three days?" A visit was classified as avoidable if the patient indicated a preference for a clinic visit. Patients were also asked, "How serious is your medical problem now?" with answers on a five-point scale ranging from "not at all serious" to "extremely serious." A visit was classified as avoidable if the patient responded "not at all serious."

Two appropriateness measures came from the nursing triage sheet. Triage nurses at SFGH categorize patients on a four-point acuity scale. Patients in triage category four are felt to be least urgently in need of care and for this analysis were classified as avoidable visits. We also studied a set of published triage guidelines from the University of California at Davis, which classify avoidable visits on the basis of symptoms and vital signs. (3-5)

Three appropriateness measures came from a review of ED medical records. A visit was classified as appropriate according to previously described explicit criteria (6) if the treating physician performed certain procedures or ordered specified therapies or diagnostic tests. Second, an emergency physician, blinded to the triage decision, rated the appropriateness of a random sample of 114 records, judging whether the patient's outcome might have been worse if care had been delayed by 24 hours. Finally, an ED visit was classified as appropriate if the visit resulted in a hospitalization.

Analysis included calculation of the proportion of ED visits deemed appropriate by each of the seven measures, along with 95% confidence intervals. In addition, each possible pair of appropriateness measures was evaluated with respect to the proportion of ED visits on which both measures agreed, and the percent agreement was adjusted for the agreement expected due to chance alone, using the kappa statistic. (7)

The proportion of ED visits deemed appropriate ranged from 10% (using hospitalization as the appropriateness measure) to 90% (using patient self-assessment). For the remaining five measures, the proportion deemed appropriate ranged from 63% to 80%, with overlapping 95% confidence intervals suggesting that these five measures deemed a similar proportion of visits to be appropriate.

However, when pairs of measures were evaluated with respect to the actual visits which they deemed appropriate, there was very poor agreement. The proportion of visits on which there was agreement ranged from 15% to

75%, with kappa statistics ranging from -0.05 to 0.31. A kappa value under 0.4 is considered poor agreement beyond that expected due to chance. (7)

The poor agreement between different measures of appropriateness raises questions about the reliability and validity of the measures. Although the study was not designed to formally assess reliability, the measures were simple and straightforward and many have been used extensively in clinical contexts or have been employed in previous studies. It appears more likely that the poor agreement reflects a problem with validity, in that the different measures failed to measure the same construct of "appropriateness."

Unfortunately, these seven measures are frequently used as if they were interchangeable. This mistaken perception that the measures are equivalent has important implications for research, health policy, and clinical practice, which will be discussed here.

Review of the literature on "inappropriate use of the emergency department" reveals substantial disagreement, with articles reporting that as few as 11% of ED visits are inappropriate (8) or as many as 82% of ED visits are inappropriate. (9) While some of this disagreement may reflect differences between the study sites, it appears likely that a substantial proportion of the disagreement is due to inadequate methodological rigor in defining and measuring appropriateness.

Turning to the health policy implications of failing to recognize the limitations of how we measure "appropriate use of the emergency department," the report from the 1992 National Hospital Ambulatory Medical Care Survey (NHAMCS) that 55.4% of emergency department visits were not urgent (1) has received tremendous media attention and has strongly influenced policy-makers. However, the media and policy-makers appear to ignore the caution subsequently expressed by the NHAMCS researchers: "Hospitals made slightly different interpretations about how they determined urgency for the survey. In some cases, the determination of urgency was based upon the severity of the patient's symptom(s); in other cases, it was based upon the patient's diagnosis or the nature of the treatment provided." (10) In other words, the researchers recognized that data abstractors at the different hospitals in their study had used different measures of appropriateness, comparable to the different measures which we compared in our study. One might therefore expect variability in which cases were classified as appropriate.

Nevertheless, policy-makers continue to discuss the construct of "inappropriate emergency department use," as if the research in this area were clear-cut. Two quotes illustrate this phenomena, "Substantial Medicaid savings could be realized by redirecting non-emergency visits to more appropriate ... sites" (11), and "Nationwide, in 1990, ... about 43 million ED visits ... could have been treated in a less expensive setting." (12)

Clinically, perception of "inappropriate emergency department visits" is manifested in emergency department gatekeeping, the process by which managed care organizations require pre-authorization for emergency department visits. Because of concerns about the clinical impact of this practice, we have undertaken a series of studies, all preliminary in nature, to ascertain the safety of emergency department gatekeeping. First, we solicited case reports of adverse outcomes occurring after managed care patients presented to emergency departments but were denied authorization for ED visits by gatekeepers representing their managed care organization. Ten case reports have been obtained to date. These include two adverse outcomes occurring after patients were denied authorization for ED visits (a patient with meningococcemia and a patient with a septic hip). One patient, with epiglottitis, was placed at increased risk after care was delayed because of a denial. There were seven "near misses," patients who were denied authorization for ED visits but who were seen anyway because of the intervention of ED personnel. In each case, a significant adverse outcome was judged to have been averted by the ED intervention. These near misses included cases of ruptured abdominal aortic aneurysm, ectopic pregnancy, cryptococcal meningitis in a patient with AIDS, pneumothorax, incarcerated inguinal hernia, gastrointestinal bleed, and an alcoholic with abdominal pain and seizures who subsequently required intensive care unit admission. (Young G and Lowe RA, unpublished data)

This series of case reports is clearly limited by the lack of denominator data; we do not know the frequency with which such events occur. Therefore, a preliminary, prospective cohort study was undertaken at the Hospital of the University of Pennsylvania. One hundred nineteen patients who were denied authorization for ED visits by their managed care gatekeepers over a three month period were included in the study. Attempts were made to contact all patients by telephone. When patients could not be reached, their primary care physicians were contacted for follow-up information. Thirty-eight patients (32%) never saw a physician after being denied ED care. Of the 64 patients we were able to reach by telephone, 18 (28%) reported that their symptoms were the same or worse than when they sought care in the emergency department. Thirty (47%) were dissatisfied with their medical care. With the telephone follow-up methodology and small sample size in this study, we did not detect any patients with adverse health outcomes, however. (13)

Our preliminary pilot studies also raised questions about the equity of ED gatekeeping. A retrospective study performed in three Philadelphia hospitals sought to ascertain which patients are most likely to be denied ED visits. Because the study relied on pre-existing data at the hospitals, methodology varied between the three institutions and only partial adjustment for patient severity and for the managed care organization to which patients belonged was possible. Bearing in mind these qualifications, we observed the odds of being denied authorization was 1.6 to 7.2 times greater for African Americans than for Whites. (14)

In summary, the concept, "inappropriate emergency department visit," remains undefined. Results of research using this concept are heavily dependent on how it is measured. Attempts to measure appropriateness of ED visits based on current methodologies may be hazardous to the validity of research and may lead to unsound health policy. There is preliminary evidence suggesting that misuse of the concept of "ED appropriateness" may also be hazardous to patients' health.

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PEDIATRIC REVISITS TO A GENERAL EMERGENCY DEPARTMENT

Deena R. Zimmerman, University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School, New Brunswick, NJ
Kevan A. McCarten-Gibbs, Denise H. DeNoble, Caryn Borger, Jacqueline Fleming, Margaret Hsieh, Jessica L. Cohen and Mary B. Breckenridge

Visits by children account for greater than one third of all emergency department (ED) visits in the US.[1] Unanticipated revisits to EDs have been used as indicators of inappropriate use of EDs, errors in medical care and lack of comprehensive health services.[2,3,4,5,6,7,8] Inappropriate use is expensive, errors are potentially dangerous and lack of comprehensive health care can be both. However, little is known about revisits of children to EDs. Two abstracts describe studies of revisits by children. However, to pediatric, not general, EDs, and one of these searched for reasons for revisits by physician questionnaires only.[9,10] In addition, insurance status has not been assessed as a risk factor for revisits in any study of revisits to date.

The aims of this study were to determine:
(1) the rate of revisits among children cared for in a general ED;
(2) what percentage of these revisits were for related medical complaints;
(3) the percentage of related revisits that were unanticipated in that the patient had not been told to follow up in the ED; and
(4) any shared demographic and clinical characteristics among those who revisit compared to the characteristics of the total population of children who utilized the study ED.

Methods

The study site was the Robert Wood Johnson University Hospital ED in New Brunswick, New Jersey, a general hospital that is the primary teaching hospital of the University of Medicine and Dentistry of New Jersey - Robert Wood Johnson Medical School. This ED treats approximately 32,000 patients of all ages per annum. It is staffed 24 hours per day by physicians trained in emergency medicine and by a pediatric attending on the evening shift. Residents in pediatrics and other disciplines are available in the hospital at all times. Comprehensive medical care is available to patients with public insurance or on a sliding fee scale at one of three clinics located within walking distance of the hospital. The two largest of these clinics provide evening appointments and 24-hour telephone access to a physician.

The data were collected from the ED records of all children (aged <18 years) who registered to be seen in the study ED from July 1, 1992, to June 30, 1993. The data abstracted include: age; race/ethnicity; gender; type of insurance; usual source of health care; date and time of visit; presenting complaint; type of physician who treated them; discharge diagnosis; disposition of patient; and instructions for any needed follow up.

Data were entered into the dBASE III+ database system. Discharge diagnoses were coded using the International Classification of Health Problems in Primary Care (ICHPPC-2),[11] an adaption of the International Classification of Diseases 9th revision for General Medicine (ICD-9-GM), devised with primary care in mind.

Repeated usage was determined by hand matching patients on the basis of street address, birth date and sex. This method was required by our IRB approval which would not allow the recording of patient names or medical record numbers.

Revisits were defined as repeated visits occurring within 14 days. A related revisit was one for a chief complaint that was considered to be related to the first, (e.g., one visit for an upper respiratory infection and another for otitis media). Unrelated revisits were those that were unlikely to be related, (eg, one visit for otitis media and a second for injuries from a motor vehicle accident). An anticipated revisit was one where the patient had been told to follow up in the ED after a defined time interval. An unanticipated revisit was one where the patient was told to follow up with their usual source of health care and/or local clinic or that no follow-up was needed and yet they returned to the ED.

Analyses, done with SAS (SAS Institute, Cary, North Carolina), included:
(a) distribution of demographic variables;
(b) chi square test of association between revisits and age, gender, race/ethnicity, and insurance status; (c) stratified analysis of these associations with Mantel-Haenszel odds ratios; and (d) odds ratios for revisits compared to non-revisits for the most common discharge diagnoses.

Census tracts of addresses were determined by matching with 1990 TIGER files for the 3 counties surrounding the hospital by the ATLAS*GIS mapping system (Strategic Mapping Corporation, Santa Clara, California). Maps of addresses of revisiters and total ED users were produced by Arcview 2.1 (ESRI, Redlands, CA).

Results:

For the one year period, 4276 children made 5228 visits. The largest proportions of visits were among those under age three (Fig. 1).

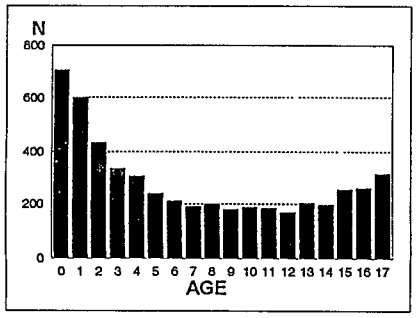


Figure 1. Distribution of Age at Last Birthday for Children Presenting to ED.

There was a slight preponderance of males (58% vs 42%). The largest racial/ethnic group was white (41.0%), followed by black (33.9%), hispanic (18.6%), and asian/other (6.5%). More than half of the population did not have private insurance (31.8% Medicaid and 18.3% none).

Distribution of time of presentation is shown in Figure 2. Pediatric attendings saw 49% of all study children.

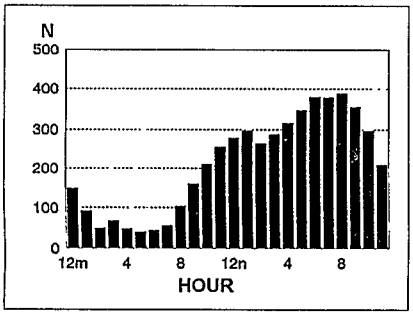


Figure 2. Time of Presentation to ED

Revisits accounted for 295 of the visits (5.6%). Of the revisits, 12% were for unrelated complaints (Fig 3). Among 206 related revisits, 82% were unanticipated. Closer examination of the 169 unexpected revisits showed 5 children had chronic diseases such as sickle cell disease and leukemia that might be expected to have frequent ED visits. Sixteen of the unexpected revisits involved a missed diagnosis. Fourteen children left without being seen one of the two times. This left 134 children who were seen in the ED for related diagnoses on two occasions within two weeks despite the initial assessment that their condition did not warrant ED follow up, and their return visit did not reveal a serious missed medical condition.

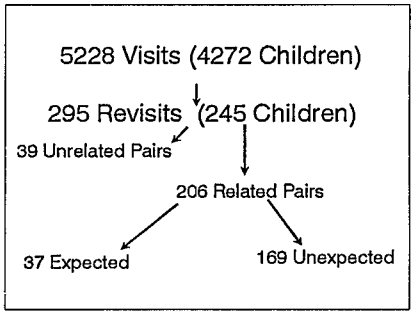


Figure 3. Distribution of Visits and Revisits by Type

The most common diagnoses among those who revisited and who did not are shown in Table I in rank order for revisits.

Table I. MOST COMMON DIAGNOSES

Diagnosis	Revisiters (%)	Non-revisiters (%)
Otitis Media	14.1	9.4
URI*	10.4	7.3
Lacerations	6.5	9.5
Asthma	5.5	3.3
Viral Syndrome	5.1	3.4
Gastroenteritis	3.7	2.0
Bronchitis	3.2	1.6
Contusions	2.9	6.2

(*URI=Upper respiratory tract infection)

Table II depicts the odds ratios of revisiting for these diagnoses. Note that those who had respiratory diagnoses were more likely to revisit and those with minor trauma were less likely to do so.

Table II. ODDS RATIOS OF REVISITING BY DIAGNOSIS

Diagnosis	OR	95% CI
Bronchitis	2.10	1.65-3.46
Gastroenteritis	1.99	1.18-3.07
Otitis media	1.60	1.24-2.06
Asthma	1.58	1.13-2.02
URI	1.51	1.13-2.02
Viral Syndrome	1.40	0.94-2.09
Lacerations	0.69	0.50-0.95
Contusions	0.45	0.27-0.75

Chi Square analysis reveals a strong association between revisits and age ($p<.0001$), insurance status ($p<.0001$), and race ($p=.007$). No association was found with gender.

When revisits were analyzed in six clinically relevant age groups (0-<2, 2-<4, 4-<6, 6-<10, 10-<14 and 14-<18) with 6-<10 as the referent group, Mantel-Haenszel adjusted odds ratios (MHOR) show that belonging to the age group 0-<2 was a strong, independent risk factor for revisits (MHOR 1.67, CI 1.27-2.19 controlled for insurance; MHOR 1.89, CI 1.47-2.47 controlled for race). MHORs with private insurance as the referent group indicate significant increased risk of revisits for public insurance (MHOR 2.57, CI 1.93-3.43 controlled for age; MHOR 2.7, CI 1.99-3.66 controlled for race). MHORs for no insurance, with private insurance as the referent group, do not reveal any increased risk for revisits.

Of the children who visited, 87.3% resided in the three counties for which we matched census tracts with addresses. Of the children who revisited, 99.6% resided in the matched counties. Among these children we successfully matched 90% of the visit addresses and 85.7% of the revisit addresses which we could have expected to match (i.e., they had complete street addresses.)

Mapping reveals a clustering of both visits and revisits to one area below the hospital but not to other areas a similar distance away nor to more distant areas within the municipalities surrounding the hospital (Figure 4).

Figure 5 is a zoomed-in view of the area immediately around the hospital. The area below and to the right of the hospital includes 5 low income census tracts. Per capita income from the 1990 census in these tracts ranges from $8,563-11,752. The number of visits from this area is even greater than indicated by the map because many children reside in a housing project, and thus have the same address, so the dots overlap. An equal distance above and to the right of the hospital are three higher income census tracts with 1990 per capita income in the range of $16,848-$24,381. Both visit rates and revisit rates were age-adjusted by direct standardization, using as the standard the sum of the 1990 age distribution for these eight census tracts. The resulting visit rate for the higher income census tracts as a group was 5.7% and for the lower income tracts as a group was 14.9%. The age-adjusted revisit rate was 0.2% for the higher group and 1.6% for the lower income group.

Discussion

The finding that 245 children (almost 6% of the study children) revisited the ED within 2 weeks indicates that revisits do form an important portion of total pediatric ED visits. Letourneau et al. found 2.6% within 48 hours, but this was in a pediatric, not general ED. Comparison of revisit rates is complicated by the different time frameworks of revisits used. The rate of revisits by children found in this study is analogous to a rate of 5.6% of elderly (>75 years of age) patients treated in an ED who were seen again in the same department within a 2 week period.[12] Two studies of all ages in Detroit showed revisit rates within 72 hours of 3.4% and 4.0%.[4,8] A Tennessee study of adults showed 3% revisits within 48 hours. Several studies in Great Britain [3,6,7] found revisit rates from 1.9-2.5% across all ages over varying time periods. Hu documented 4.9% within one week in a veterans' hospital in Taiwan.[5] For these studies, the different medical system and population many have influenced the rates of revisits found. A study of all revisits to the same institution, analyzed by age, would be needed to determine if children are at particular risk for revisits.

The finding that 5.4% of this study's

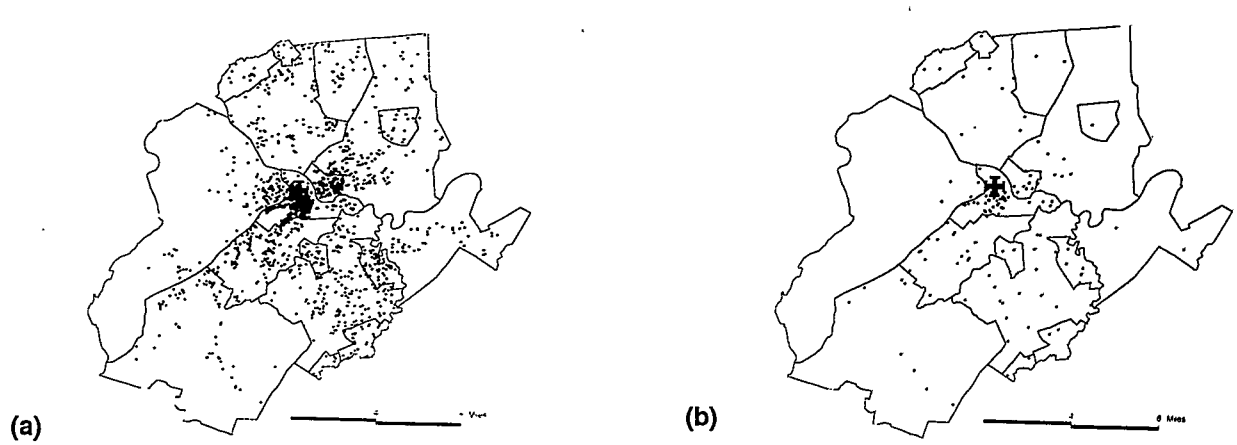
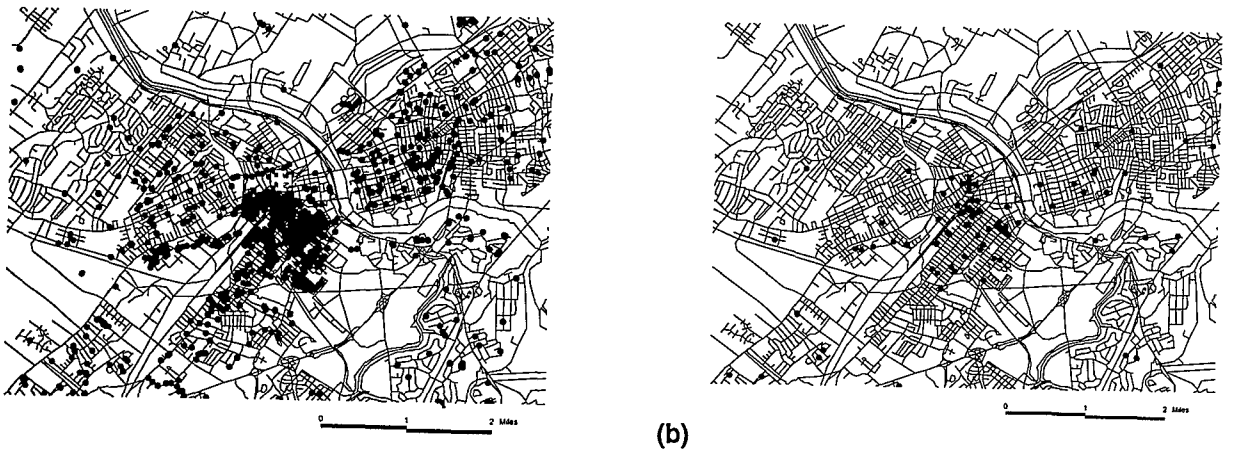


Figure 4. Map of municipalities surrounding the hospital showing (a) all visits and (b) revisits from this area.



(a) (b)

Figure 5. Zoomed-in view of area around hospital showing (a) all visits and (b) revisits.

visit-revisit pairs involved a missed diagnosis can be compared with the rates of 9% found by O'Dwyer[7] and 11% found by Keith[8] for the general ED population. Keith found only 1.4% of missed diagnoses in single visits to their ED compared to the 11% among revisits, and thus concludes that revisits, in particular unanticipated revisits, form a fruitful area for quality assurance. We did not assess the overall statistic of missed diagnoses in our ED, but agree they form an appropriate flag for quality assurance efforts.

Our finding that among the five diagnoses with greatest risk of revisiting, four were for respiratory illnesses suggests that parents may have particular concerns about these illnesses and require repeated reassurance.

Unanticipated revisits without change in diagnosis were the major proportion of pediatric revisits in this general ED. The preponderance of unanticipated revisits was true for the studies of revisits among adult patients as well.[2,3,4,5,6,7,8] Since revisits could represent care better delivered in other settings, this deserves further research.

None of the other available studies of revisits have analyzed insurance status as a risk factor for revisits. This is partially because many of these studies are from countries with national health insurance (England, Scotland, China) where differences in insurance status would not be a relevant factor. Those studies from the United States [2,4,8,10] did not report on the insurance status of the revisiting patients. Our finding that public insurance is a risk factor for revisits to the ED, even when controlled for age and race, suggests these patients may be less likely to have a primary source of health care that is available 24 hours a day. However, the local clinics do have 24-hour telephone access to a physician. Whether patients utilized this prior to their ED visits requires further research.

If lack of access to a regular source of health care were the only reason for ED revisits, one would expect that patients with no insurance would also be more likely to revisit the ED. However, this was not found to be the case in this study, suggesting that the requirement of paying out-of-pocket is a disincentive to ED use. Our finding of a markedly higher age-adjusted revisit rate for the poorer census tracts near the hospital than for other tracts equidistant from the hospital but of higher socioeconomic means argues against greater incidence of revisits being simply a matter of logistics.

Possible reasons for the observed higher revisit risk of children less than two may be that parents are more concerned by symptoms such as fever in younger children than in older children, and/or the diagnosis is more difficult in younger children, leaving the parents less convinced of the original diagnosis and thus more likely to return for a reevaluation.

Conclusions:

Almost 6% of children who visit this ED revisit within 2 weeks. Most of the revisits are unanticipated and are related to the reason for the first visit. Most revisits can not be explained on the basis of medical need. There is a greater risk of revisit for respiratory diagnoses and a lower risk for minor trauma. Public insurance is a risk factor for revisiting. Children aged <2 and residents of poorer census tracts are more likely to both visit and, for some tracts, to disproportionally revisit the ED. As our study was a chart review, we were unable to determine whether parents chose to revisit the ED because of lack of understanding of discharge instructions for follow up, lack of transportation to alternate sites, need for reassurance, or preferance for the ED as a source of care. Further study is needed of such parental decision making.

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TRIAGE ACUITY CLASSIFICATION: DECISION MAKING BY EMERGENCY NURSES

Susan L. MacLean, Emergency Nurses Association
Catherine Ferrario, Kevin Kissane, Claudia Jorgenson, Paula Tanabe

One of the first persons that patients and families encounter on arrival in many emergency departments is the triage nurse. In a comprehensive triage system, the triage nurse sorts patients by severity of condition and determines priority for therapeutic intervention. Accurate triaging can decrease mortality and morbidity and lower the costs of care. On the other hand, over-triaging less urgent patients may waste expensive facilities and personnel and possibly delay the care to more seriously ill patients. Under-triaging can increase the risk of patient mortality and morbidity.

Triage Acuity Classification

The triage nurse must accurately and rapidly sort the small numbers of seriously ill from those individuals whose conditions are less serious and can tolerate delays in treatment without compromising safety. Based on assessment data, the nurse determines the patient's acuity and assigns an acuity category.

While there are many different classification schemes, in general, the acuity category conveys the degree to which the condition is life or limb threatening; the risk for short term complications; and the availability of treatment resources and providers (ENA, 1992). For example, in a three category acuity scheme (ENA, 1992) patients would be classified as emergent if their condition was immediately life or limb threatening. An urgent category would be assigned to a patient that required prompt care but could wait several hours without threat to life or limb. With the non-urgent patient, time is not a factor. These patients are able to wait for treatment without compromising safety. Thus, the acuity category reflects the seriousness and urgency of the patient's condition in relationship to other patients and available resources in the emergency department.

Triage Decision Making Study

The triage systems that are used by nurses have evolved primarily from clinical experience and from knowledge gained from military and disaster systems (ENA, 1992). Unfortunately, little research has been done related to emergency department triage. Therefore, we conducted a study examining the decision making of 26 triage nurses in a comprehensive urban university medical center emergency department that provides services to 40,000 patients annually. Patient, nurse, environmental, and task variables that influenced triage decision making were assessed in 115 patient encounters.

Following each triage, the nurses were asked to describe their thinking related to the triage decision making. Qualitative analysis of each audio-taped debriefing was completed by two investigators. In addition, other data were collected from patients' emergency department records concerning the patient, task, and environmental factors.

To determine the accuracy of the triage acuity category assigned, the nurse's assessment data, hypotheses, domain of information searched, triage category selected, placement decision and patient wait time were compared to the patient's initial and discharge medical diagnoses, interventions, and discharge destination. Consistency of decision making among these factors was an indicator of accurate triage. If there were inconsistencies in the data during the course of the ED visit, the reason for the inconsistency was evaluated. For example, if the triage acuity category assigned was unstable urgent but the patient was not admitted to the hospital, the inconsistency would have been evaluated. Using these accuracy criteria, we found that nurses were highly accurate in their prioritization of patients and their assignment of the triage acuity category. In two cases an alternative acuity category was suggested by one of the coders, however, both coders agreed that the category was acceptable as used. Therefore, based on the study emergency department's definitions for triage acuity, the nurses correctly separated patients into four categories: emergent, unstable urgent, stable urgent, and non-urgent (i.e., discrimination). In addition, the nurses showed agreement between predicted and observed triage outcomes, (i.e., calibration). In other words, the prediction of seriousness, urgency and risk at triage was consistent with the seriousness, urgency, and risk that was observed during the patient's emergency visit.

Local Versus National Acuity Data

Following triage, the nurse's acuity rating conveyed valuable information to the other health providers in the treatment area. Everyone in the emergency department knew what an unstable urgent patient was and the resources that were needed to

provide care to this patient. The triage acuity data in the study ED clearly met the needs of the patients and health providers in this setting. Unfortunately, comparisons between this excellent local triage acuity data and other emergency departments' data cannot be made. This local data cannot be aggregated with other ED triage acuity data to project trends in health care needs and allocation of resources. It cannot be used to guide decision making for national health standards and policy.

Inadequate data. There are several reasons why triage acuity data cannot be aggregated and compared across settings. In many emergency departments, there are no data. The Emergency Nurses Association (ENA) is in the process of surveying 4,364 emergency departments concerning their demographic characteristics, services, and issues (ENA, 1995). The preliminary results showed that 14% of emergency departments do not use triage acuity categories, 18% do not document the acuity data, and only 5% document acuity on a computer. Developing national statistics is impossible when data are not documented or are documented but are very difficult and time consuming to retrieve.

One solution to the lack of data will be addressed by the development of a uniform emergency department data set. The Emergency Nurses Association (ENA) is currently developing an emergency nursing uniform data set that identifies the essential and desirable data elements that all emergency nurses should collect on patients. The ENA also is helping to sponsor and participate in a multidisciplinary group led by the Centers for Disease Control (CDC) to develop a national emergency department uniform data set. In these data sets, triage acuity classification has been suggested as an essential data element, collected on all emergency patients, and uniformly defined.

Definition variation. Another problem with the current triage acuity classifications is that emergency departments use systems with different categories, criteria, and definitions. In the preliminary ENA survey data (ENA, 1995), about a third of the EDs used a 3-category system, that is, emergent, urgent, and non-urgent categories or red, yellow and green categories. Other systems included a 1 to 5 classification, a 1 to 4 classification, and a few used some other acuity system. Furthermore, these systems are not defined in a logical hierarchy (Anderson & Lees, 1978). For example, it is not possible to collapse most 5-category systems down to a 3-category system for statistical comparisons. In summary, the lack of data and the variations in triage acuity classifications have prevented the accumulation of data concerning the acuity of patients in emergency departments across the nation. This lack of comparable data is a significant problem. Health care is rapidly changing and a national database of information is needed for making important ethical, economic, and health care resource decisions.

Research Directions

Currently, there has been no methodological research done on the development and testing of a triage acuity classification. However, several authors have provided direction for this type of research (Brannen, Godfrey, & Goetter, 1989; Cowen & Kelley, 1994; Ruttimann, 1994). The first priority for research on triage acuity classification is to develop consensus on the standard for the acuity criteria, categories, and definitions. Further, there is a need for research to identify the predictor variables and outcome states associated with each of the acuity categories. Next, the triage acuity system that is developed needs to be tested for accuracy, discrimination, and calibration. Determining sensitivity and specificity and error rates of the prediction rule should be done. Because of the risk to emergency patients, the potentially life-threatening problems associated with prediction errors must be assessed. Finally, the triage acuity classification system needs to be evaluated on a large, broad sample of emergency patients. The results of this research program will be a triage acuity classification that is accurate, efficient, and effective for communicating information concerning all types of patients and in all types of emergency departments.

With a national standardized system for triage acuity classification in emergency departments, data will be available to guide health reform, provide quality emergency care, improve health outcomes, and enhance emergency health services utilization.

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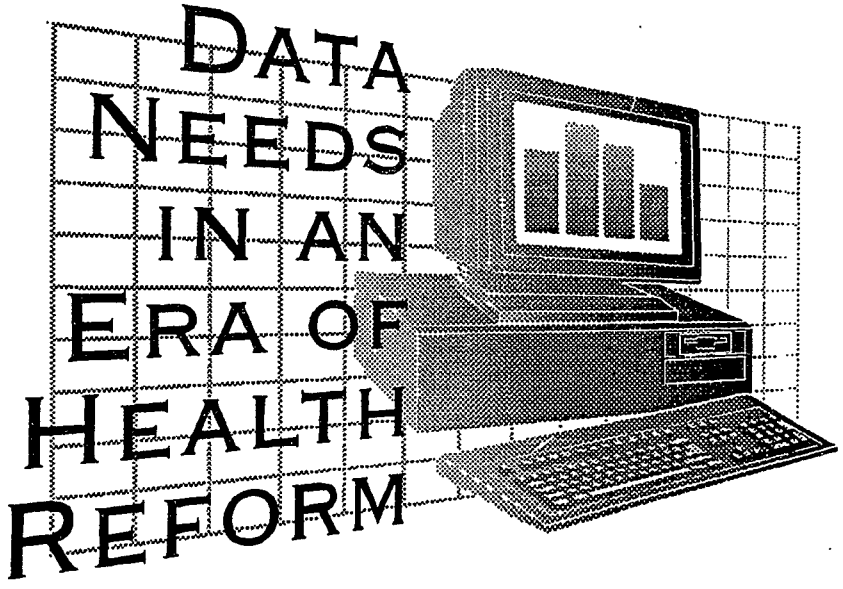
EMERGENT CARE
Discussant

Robert M. Williams, University of Michigan School of Public Health

Comments not available for publication.

Session H

Breast Cancer



ASSESSING BREAST CANCER RISKS AND PREVENTIVE BEHAVIORS AMONG WOMEN VETERANS

Denise Hynes, Edward Hines Jr. VA Hospital and Loyola University Chicago
Lori Bastian, Richard Sloane, William Kalsbeek, Barbara Rimer, and
John Feussner

Cancer incidence among women veterans has been estimated to be twice that of the general population (Harris and Associates, 1985), yet scant research has examined the cancer risk profiles or the health behavior of this seemingly high risk population. In particular, no research has examined women veterans' risk or behavior patterns for breast cancer-a cancer that will be second only to lung cancer as the cause of death in women in 1995 (ACS, 1995). This study sought to assess breast cancer risk factor profiles and preventive health behavior patterns among women veterans across the United States.

Background

A number of factors are known to increase the risk for breast cancer in the general population, some which can be modified (Willett, et al., 1987; Newcomb, et al., 1994; Hurstin, et al., 1990; Hiatt, et al., 1988; Lowenfels, 1989; Longnecker, et al., 1988; Gail et al., 1989; Romieu et al., 1990; Delgado-Rodriguez, et al., 1991; Steinberg, et al., 1991; Dupont and Page, 1991; Howe, et al., 1990; Rushton and Jones, 1992; Silleros-Arenas et al., 1992; Lemon, et al., 1992), and others which allow targeting for secondary prevention (Kelsey, et al., 1991; Brisson, 1991; Mittra and MacRae, 1991; Ewertz, et al., 1990). Modifiable risk factors include dietary fat, excessive alcohol consumption and smoking. Breast cancer risk factors that are not amenable to primary prevention, but serve as identifiable characteristics for screening and regular monitoring include older age, estrogen related factors, North American or Northern European ancestry, and family history of breast cancer (Kelsey and Gammon, 1991). While a consensus exists regarding some risk factors for breast cancer, there is uncertainty about other factors.

At present, early detection is the most effective method of secondary prevention. For example, when breast cancer is detected early in stage I (i.e., tumor diameter less than 1 centimeter with no cancerous nodes), 80-90% of women will remain free of recurrence (Wertheimer, et al., 1986). Clinical breast examination and mammography have been clearly established as effective screening tests for breast cancer (Shapiro, et al., 1988; Tabar, et al., 1985), with mammography being the most sensitive (Health After Age 50, 1990). While the effectiveness of screening programs may be sensitive to the incidence of breast cancer in the population (Nutting, et al., 1994), studies have shown that if women followed mammography screening guidelines, breast cancer deaths should decline by at least 30% (Tabar, 1985). Among women aged 50 and older, screening programs that include regular mammograms can reduce mortality from breast cancer by as much as 40% (Tabar, et al., 1985; Shapiro, et al., 1985). While the benefit of mammography after age 50 has been conclusively demonstrated, whether to initiate mammography at age 40 or 50 remains controversial (ACS, 1988; NCI, 1987; CTFPHE, 1979; Frame, 1986; Eddy, et al., 1988; Dodd, 1992; Kerlikowske, et al, 1995).

While there has been substantial improvement in the use of mammography screening for women in general over the last five years (Breen and Kessler, 1994), minority women and poor women still have rates that are low (Fox, Siu & Stein,1994; Perez-Stable, et al., 1994; Zavertnik, et al., 1994). For example, in 1991, it was reported that more than half of women over age 40 had neither received a mammogram (GAO, Dec, 1991) nor were participating in regular screening (Marchant and Sutton, 1990).

The number of women in the military and veteran population has risen in the last ten years. As of 1995, there were nearly 200,000 women serving in the military (Office of the Secretary of Defense, 1995), and the number of women choosing careers in the military continues to increase. Similarly, the number of female veterans has increased in recent years, totaling an estimated 1,234,300 as of 1991 DVA, 1991; Harris and Associates, 1985), with over 45,000 female veterans receiving compensation for service-connected conditions. Many of these beneficiaries are women over 50 years of age who are at greater risk of breast cancer.

Methods

We surveyed a national sample of women veterans by telephone to evaluate breast cancer risks and preventive behaviors. This survey is the first phase of a larger national survey. The sample was selected from a list of women veterans constructed from databases from the Defense Manpower Data Center, the Internal Revenue Service and national VA databases at the Austin Automation Center, and represents all living women veterans discharged from the military between 1971 and 1994. A two phase sampling approach was used. The first phase sample comprised a 10% sample of all women veterans age 35-70 years at the time of discharge from the military, who served at least 18 months and were discharged between 1971 and 1994. 20,000 were sampled from the list of women veterans meeting these criteria. A 3x2 stratification scheme was used: 3 age groups (35-49,50-64,65+) and 2 VA user groups indicating whether they received any health care from a VA Medical Center (VAMC) in the last five years (VA user) or not (VA non-user).

The questionnaire addressed breast cancer risk factors, including medical history, environmental and occupational exposures, diet, exercise, alcohol and tobacco use; use of mammography and other screening practices; perceptions about women's health care at VA medical centers, military service characteristics, and sociodemographics. Validated items from the Survey of Women Veterans and NCI's Health Habits and History Questionnaire (HHHQ) were included.

To locate women effectively and improve response rates we used aggressive tracking approaches including multiple data sources for locating subjects and scheduling call back times for conducting interviews. 98% of the women were located using these tracking techniques. Response rate was 75% (297/397). Seven women were excluded because they reported that they were not in the military for at least eighteen months, for a total of 290 interviewed respondents.

All respondents were interviewed by a female interviewer. The first 100 women contacted were administered the full survey (102 items). The remaining women contacted were administered a brief 15 item survey focusing only on the breast cancer screening questions and some basic demographics. For our analyses, the first 100 responses were available for the risk factors, and all 290 responses for the breast cancer screening questions were used.

Table 1
Frequency of General Risk Factors for Women Veterans Compared to the General Population

RISK FACTORS	WOMEN VETERANS (N=100)	GENERAL POPULATION STUDIES
First degree relative with breast cancer	12%	11% (Gail, et al., 1989)
Presence of benign disease	32%	12-24% (Gail, et al., 1989; Newcomb, et al., 1994)
Lactation	57%	54% (Newcomb, et al., 1994)

Table 2
Frequency of Lifestyle Risk Factors for Women Veterans Compared to the General Population

RISK FACTOR	WOMEN VETERANS (N=100)	GENERAL POPULATION STUDIES
Ever used alcohol	54%	68% (Willett, et al., 1987)
Ever smoked cigarettes	61%	56% (Willett, et al., 1987)

Table 3
Frequency of Risk Factors for Elevated Estrogens for Women Veterans Compared to the General Population

RISK FACTOR	WOMEN VETERANS (N=100)	GENERAL POPULATION STUDIES
Menarche before age 12 years	17% (Mean age 12.8 years)	15% (Gail, et al., 1989)
First child at or after age 30 years	33%	11% (Gail, et al., 1989)
Never had children	50%	25-30%
Late menopause (after age 50)	21%	30% (Newcomb, et al., 1994)

Table 4
Frequency (Weighted) of Advice About Mammography Screening By Age Group (N=290)

	Age Group	
Advice Variable	35-49 Years (N=135)	50 Years and Older (N= 155)
Did a doctor or a nurse ever discuss the need to have mammography with you?	72%	82%
Did a doctor or nurse ever tell you to have a mammogram?	66%	77%

Table 5
Frequency (Weighted) of Use of Mammography By Age Group (N=290)

	Age Group	
Mammography Use Variable	35-49 Years (N=135)	50 Years and Older (N= 155)
Have you ever had a mammogram?	72%	92%
Mammogram within the past two years	47%	79%

Table 6
Predictors of Mammography Use Within the Past Two Years (N=290)

PREDICTORS	ODDS RATIO	CONFIDENCE INTERVAL
Age 50 Years or greater	2.52	1.35-4.67
Length of Service 36-114 months	0.86	0.47-1.59
Length of Service more than 114 months	2.17	0.98-4.77
Black Race	0.83	0.37-1.88
Used the VA within the last five years	1.58	0.92-2.70

For purposes of this presentation, the 35-49 year olds were compared to those 50 years and over, for all analyses.

Results

1. Risk Factor Prevalence

To put our results in context, where possible, we compare them with published literature on non-veteran female populations. Tables 1-3 show results for the frequencies of specific risk factors among the 100 women veterans interviewed. For example, Table 1 for general risk factors for breast cancer, 12/100 women veterans surveyed in our pilot study reported a first degree relative with breast cancer compared to 11% in the Nurse's Health Study (Newcomb, et al., 1994).Other factors, although weaker than having a family history of disease, include the presence of benign disease and breast-feeding. In our survey, more women veterans reported having these risk factors than other published studies: 32/100 women veterans in our pilot reported a presence of benign disease compared to 12-24% reported in other studies (Newcomb, et al., 1994; Gail, et al., 1989). Experience with lactation, that is ever having breast fed an infant, was 57% among women veterans compared to 54% in the Nurse's Health Study.

Table 2 presents the lifestyle factors for women veterans compared to other published studies. Of the women veterans surveyed 54% drank alcoholic beverages compared to 68% in the Nurse's Health Study (Willett, et al., 1987). 61% of women veterans surveyed had ever smoked, compared to 56% in the Nurse's Health Study (Willett, et al., 1987).

Table 3 presents results for risk factors related to elevated estrogens. Of women veterans surveyed 17% reported having late menarche (mean age was 12.8 years of age); 33% had their first child after age 30 and 50% had no children. These rates were higher than women in other studies (Gail et al., 1989; Newcomb, et al., 1994).

2. Advice About Mammography

Table 4 presents results for the 290 women who were asked about the advice they received regarding their personal need for mammography, by age group. Among women age 35-49, 72% reported that they had a discussion with a nurse or a physician about the importance of mammography and 66% reported that they were instructed to have a mammogram. Comparatively, women 50 years and older reported higher rates: 82% had a discussion about mammography with a nurse or a doctor and 77% were told to have a mammogram.

3. Use of Mammography

Table 5 presents results for the 290 women respondents use of mammography, by age group. Among women age 35-49 72% reported that they had ever had a mammogram. 47% reported that they had a mammogram within the past two years. Comparatively, among women age 50 years and older, 92% reported that they had ever had a mammogram and 79% reported that they had a mammogram within the past two years.

Table 6 presents results for the regression model for predicting mammography use within the last two years. Older women were 2.5 times more likely to have had a mammogram in the past two years than younger women(Odds Ratio 2.52, Confidence Interval 1.35-4.67). Women veterans who had been in the military a long time, that is, more than 114 months, were 2.1 times more likely than women who had been in the military less than 36 months (O.R.:2.17; C.I.: 0.98-4.77). Whether a women veteran had ever used the VA for health care was significant at the $p<0.10$ level and race was not statistically significant. Only 4% of respondents were black.

Discussion

The risk factor profile for women veterans appears different than that found in general population studies. The women veterans tended to have higher frequencies for general risk factors and for risk factors for elevated estrogens. Lifestyle factors for women veterans compared to general population studies were lower for alcohol consumption but higher for cigarette smoking. As a pilot study, we surveyed only 100 women from across the United States about risk factors, and thus statistical comparisons are not appropriate. These trends should be further investigated in a larger study.

Regarding advice about mammography, women veterans are aware of the need for early breast cancer screening, but may not always heed this advice. In our survey some women reported that they thought that mammography was only necessary when a lump was felt on clinical breast examination. There is a clear need for education and outreach among women veterans regarding breast cancer prevention and early detection. It is not clear from this research if special efforts are needed to reach this particular population, but further study is warranted to evaluate the best methods for reaching women veterans

Regarding use of mammography, women veterans are reporting slightly lower rates of adherence than reported in studies of non-veteran populations. In addition if women veterans are a higher risk population more frequent screening may be desirable in this population.

Regarding predictors of mammography usage, our results are consistent with the notion that women in the military have health screening while in the military and practice this behavior after leaving the military. Further research should evaluate not only the length of time in the military, but also the time since discharge and whether any breast cancer screening actually occurred when a women was on active duty in the military.

Conclusions

This study is among the first to examine breast cancer risk and preventive behaviors among women veterans. These issues are important because the female veteran population is aging, making them more at risk for breast cancer, and the female veteran population is growing as more women enter the military. With the growing number of young women currently in the military and the growing number of elderly women veterans, the demand for women's health care services within the VA health care system in particular, will increase. Prevention and treatment for cancers affecting women veterans--most notably breast cancer--will have an increasingly significant impact on VA and non-VA health care. Further research is needed to examine the needs and impacts of this potentially high risk population of women.

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MAMMOGRAPHY UTILIZATION IN HAWAI`I - A POTENTIAL USE OF INSURANCE CLAIMS DATA

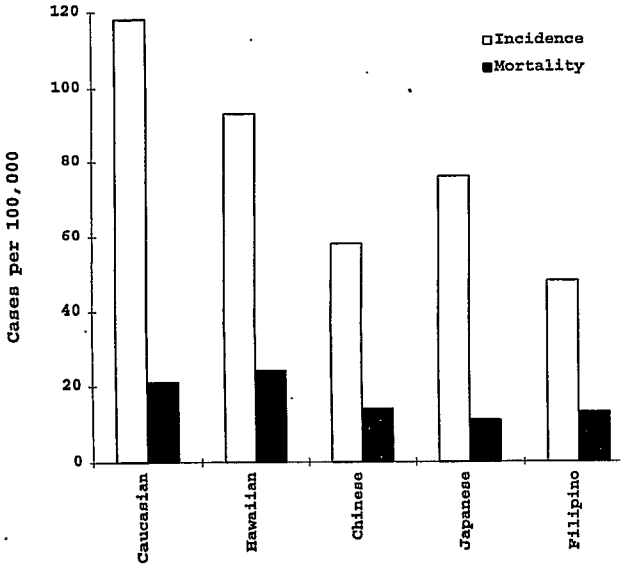
Gertraud Maskarinec, Cancer Research Center of Hawai`i
Lixin Meng

ABSTRACT

The purpose of this paper is to illustrate the use of health care data for breast cancer prevention. To increase participation in mammography screening programs, characteristics of women with low utilization patterns need to be identified. Telephone surveys are commonly used to assess participation in screening programs but their small sample size and their lack of geographic information preclude analysis below the state level. This ecologic study combines insurance claims and census data to analyze geographic variations in mammography utilization.

Insurance claims data for 1992 and 1993 from 3 private and 4 public payors, covering close to 85% of the state's female population, were combined with the 1990 Census ZIP File. It was estimated that between 30 and 50% (median = 42%) of women 40 years and over had received at least one mammogram during the two-year period. Characteristics of geographic areas with low utilization were identified. Results from this study will be useful in targeting prevention strategies and surveillance and evaluation.

Figure 1. Breast Cancer Incidence and Mortality, Hawai`i, 1986-1990



INTRODUCTION

As in most U.S. states, breast cancer is the most common female cancer in Hawai`i; close to 700 cases (in situ cases included) are diagnosed annually (Hawai`i Tumor Registry, unpublished report). In the absence of an effective primary prevention strategy, early diagnosis through mammography and breast exam remain the major approach to decrease morbidity and mortality from breast cancer. Whereas participation in mammography screening has been increasing over the last 10 years[1], many women have not been making use of this early detection method.

Hawai`i's multiethnic population includes persons of Hawaiian, Japanese, Chinese, Filipino, and Caucasian ancestry. Data from the Hawai`i Tumor Registry indicate ethnic differences in breast cancer diagnosis and survival that might be due to differences in screening and early diagnosis. Compared to the respective incidence rates, mortality rates are disproportionately high for some ethnic groups (figure 1). Survival after diagnosis is shorter for

Figure 2. Breast Cancer Survival by Ethnicity, Hawai`i, 1983-1988

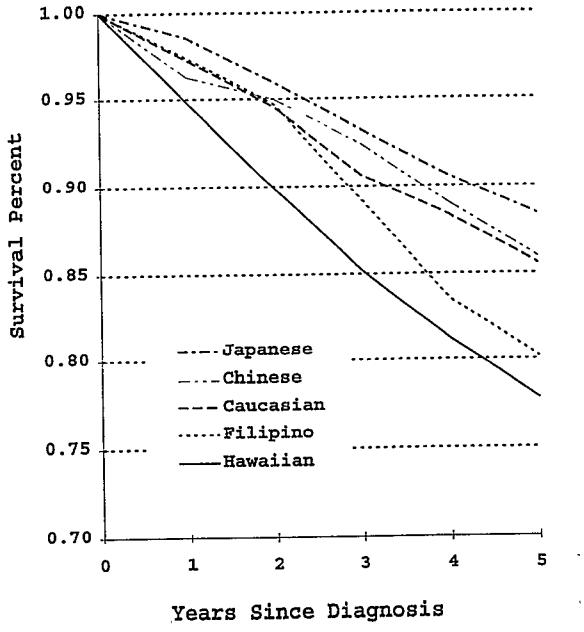
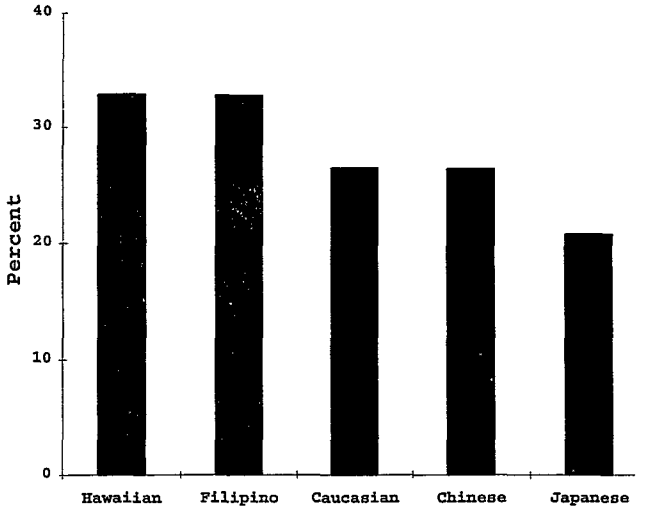


Figure 3. Breast Cancer, Hawai`i, 1989-93, Percent Diagnosed at Stage 2 or Above



women with Hawaiian and Filipino ancestry (figure 2), possibly because more of them are diagnosed at a later stage (figure 3).

To increase participation in mammography screening, it is useful to identify geographic areas or population groups with low participation. Mammography utilization has been mostly assessed through self-reports, such as the Behavioral Risk Factor Survey System (BRFSS)[1] with all its limitations. Billing information from insurance carriers should be able to provide more accurate information. Hawai`i is an ideal place to conduct research using insurance claims data for several reasons. Because of the state's island nature, most of the health care is received within the state. Insurance coverage is high, only 4% of the population are estimated to be uninsured (table 1)[2], and the number of insurance carriers is small.

Insurance claims data have the advantage of being relatively economical since they have been collected already and put into an electronic format. They cover large segments of the population, allow follow-up, use standardized codes (ICD-9 for diagnosis and CPT95 for procedures), do not need informed consent, and are free of recall bias[3,4].

Table 1. Hawaii's Health Insurance, 1993

CATEGORY	MEMBERS	PERCENT NET RESIDENT POP
PRIVATE BUSINESS		
HMSA	604,674	53.7%
Kaiser	187,889	16.7%
Commercial	55,500	4.9%
Queen's Plan	45,000	4.0%
HDS-Medical	50,500	4.5%
Island Care	16,662	1.5%
TOTAL	**960,225**	
GOVERNMENT PROGRAMS		
SHIP	21,843	1.9%
CHAMPUS	84,800	7.5%
Medicare	126,387	11.2%
Medicaid	110,812	6.8%
TOTAL	**343,842**	
PRIVATE + PUBLIC	1,304,067	115.7%
UNINSURED	46,201	4.1%
TOTAL COVERAGE	**1,350,268**	**119.8%**
POTENTIAL OVERLAP	223,418	19.8%
RESIDENT POP	1,126,850	

This ecologic study has three objectives:

1. To determine mammography utilization rates for 1992/1993 by age and geographic area.
2. To identify characteristics of areas with low utilization rates.
3. To illustrate the use of insurance claims data for breast cancer prevention.

METHODS

Typical data elements of an insurance claim include patient information (name, account & member number, sex, birth date, zip code of residence, and SSN), encounter information (date of service, up to 5 diagnostic and procedure codes, charges), and provider information (provider ID and specialty). This project did not utilize any identifying or financial information. Mostly scrambled account numbers were used to track women over the two year period. Therefore, it was impossible to identify any individuals and complete confidentiality was maintained at all times. This study was approved by the review boards overseeing the insurance carriers. Data were collected for an estimated 82.5% of the state's population. Information could not be obtained for the uninsured, for the military population, and from some small commercial carriers.

To identify mammographies, claims with the following procedure codes were extracted from the different data bases:

8737 Mammography
40100 Diagnostic Mammography
40300 Screening Mammography
Z5026 Health Appraisal A, Mammography
Z5027 Health Appraisal B, Mammography
Z5030 Health Pass Mammogram
Z5030 Screening Mammography
76090 Diagnostic Mammogram, unilateral
76091 Diagnostic Mammogram, bilateral
76092 Screening Mammography

Theoretically, it is possible to separate diagnostic from screening mammograms. However, it became apparent early in the project that many providers are using diagnostic codes for screening mammograms. Until 1991, when insurance coverage of screening mammography was mandated by the legislature, codes for diagnostic mammograms were used in order to be reimbursed and not all providers have changed their coding practice since then. Therefore, all mammograms regardless of coding are included in this study.

Data processing included deleting duplicates and claims with invalid ZIP codes, combining data sets from the different private and public payors, keeping one claim per women per year (any additional would not be screening mammograms), producing frequency tables by ZIP code, and combining data sets with the 1990 ZIP census file. Approximately 3.5% of claims had ZIP codes designating post office boxes rather than geographic areas. If possible these claims were assigned the ZIP code of the geographic area that includes the particular post office. Utilization rates were calculated by dividing the number of women with at least one mammogram during 1992/93 by the estimated number of women living in the geographic area.

As denominator, the 1990 census ZIP file on CD-ROM as distributed by the Census Bureau was used. It provided information on the number of women by age, ethnic distribution, income, and educational achievement. Since intercensal estimates are not available for individual ZIP code areas, the population size was increased by the statewide population growth rate for women 40 years and over as published annually by the Census Bureau.

Table 2. Data Sources for Mammography Claims, Hawai`i, 1992-93

Payor	1992	1993
Private 1	33,932	37,335
Private 2	1,254	1,139
Kaiser	13,678	18,077
Medicare	10,292	9,819
Medicaid	1,799	1,997
CHAMPUS	510	407
Total	**61,465**	**68,774**

Multiple linear regression using the stepwise method was utilized to develop models with mammography utilization rate as dependent variable and demographic information and insurance membership as independent variables. Variables with a non-normal distribution were transformed by an appropriate operation. Data management and analysis were performed with PC-SAS® (SAS Institute, Cary, NC).

RESULTS

A total of 61,465 and 68,774 mammography claims for women 40 years and over were obtained for 1992 and 1993 respectively (table 2), after deleting repeat mammograms during the same year. The median mammography utilization rate is 42%. After weighting by population size, most ZIP code areas have a utilization rate between 30 and 50% (figure 4). Rates differ by age group but very little by year (figure 5). 26% of all women had more than one mammogram during the two year period. This percentage was higher for women between 50 and 64 years (32%) than for women 65 years and over (25%) and women 40 to 49 years (18%). Mapping the utilization rates illustrates geographic areas with high and low utilization and will be useful for future interventions (figure 6).

A comparison of self-reported mammography utilization rates from the Behavioral Risk Factor Survey System with results of this study (figure 7), suggests that self-reports are at least 20% higher than estimates from insurance claims data.

Figure 4. Mammography Utilization by ZIP Code Area, Hawai`i, 1992-93

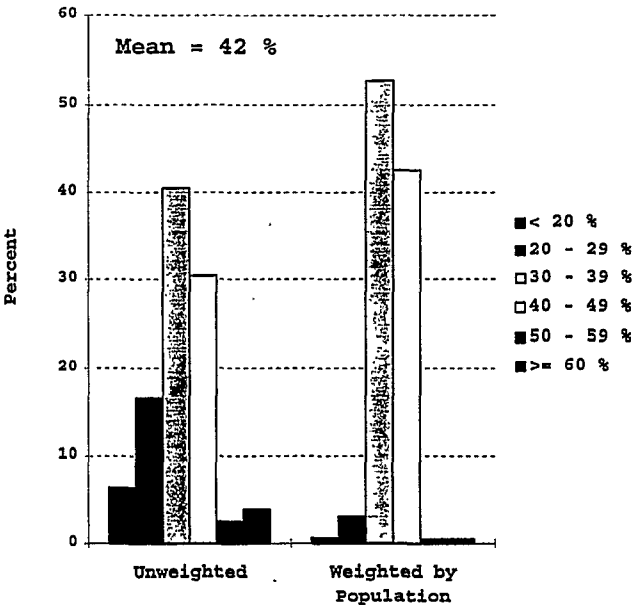
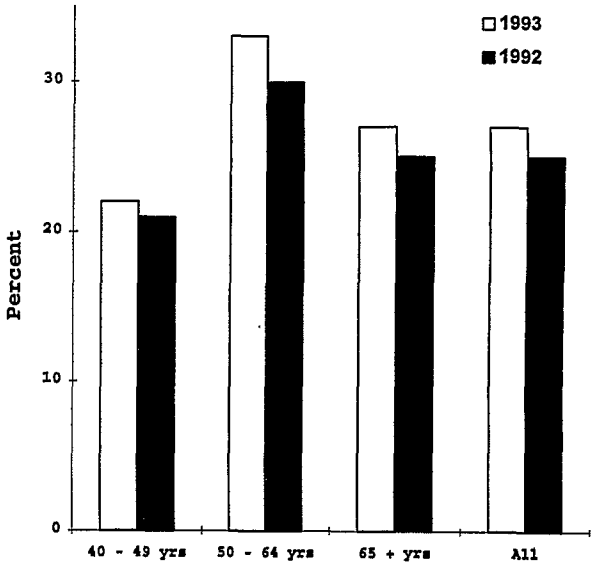


Figure 5. Mammography Utilization Rates by Year and Age, Hawai`i, 1992-93



The best regression model with only demographic variables explains 24% of the variance. It includes low income (<$30,000 household income per year), percent Japanese in the population, and urban environment. A combined model explains 56% of the variance. It includes Blue Cross Blue Shield coverage, low income, urban environment, and Kaiser coverage. Age, county of residence, percentage of other ethnic groups, the presence of a mammography unit in ZIP code area, and educational achievement are not significant in any of the regression models.

Figure 6. Mammography Utilization Rate
By Zip Code, Oahu, Hawai'i, 1992-93

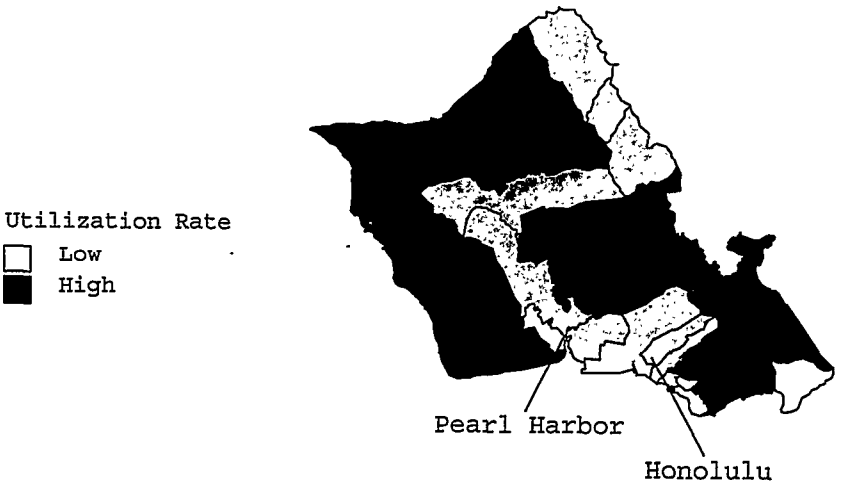
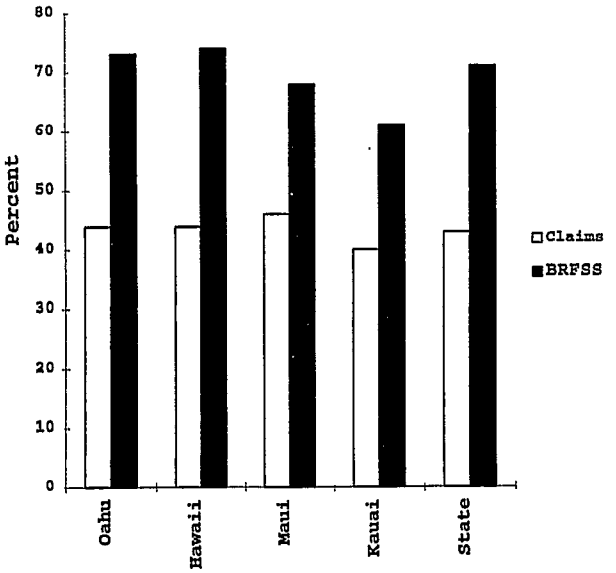


Figure 7. Mammography Utilization, Hawai`i,1992/93
Comparison of BRFSS and Claims Data



DISCUSSION

This study estimates that at least 42% of women 40 years and over had a minimum of one mammogram during 1992/93. Adjusting for the unavailable data, the percentage may be as high as 50%. In the BRFSS, 71% of women 40 years and over reported a mammogram during the most recent two years. This overestimate is probably due to selection and recall bias in the telephone survey. The geographic variation in utilization rates was surprisingly small. Demographic information from the census file was not a good predictor of utilization rates. Geographic areas with low mammography utilization were more likely to have low Blue Cross and Kaiser coverage, a high percentage of households with low income (<$30,000), a low percentage of persons with Japanese ancestry, and to be in an urban environment.

The major limitation of this study is that data are unavailable for 17% of the population, mostly for the military and the uninsured population and for persons covered by small private carriers who are unable or unwilling to share their data. The lack of a unique identification number is another serious problem because it makes it impossible to quantify dual insurance coverage, estimated at 19% in Hawaii, and to track individuals when they change health plans. Accurate denominators for intercensal years on ZIP code level would also be desirable. Insurance claims do not contain information on ethnicity which makes it impossible to calculate ethnic-specific utilization rates. Ecologic models using the percentage of certain ethnic groups by ZIP code as done here cannot assess ethnic differences in mammography utilization with great accuracy.

In the future, the results of this study will be linked to breast cancer incidence and mortality data on a geographic level. This data set will be useful to monitor time trends in mammography utilization and as a surveillance tool to evaluate interventions to increase participation in mammography screening. Insurance claims have great potential in the area of cancer prevention mainly because they allow assessment of participation in cancer screening for population subgroups and specific geographic areas.

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MEASURING MAMMOGRAPHY SCREENING GUIDELINES BY DIVISION IN AN INTEGRATED GROUP PRACTICE

Diana M. Rademacher, Mayo Clinic, Mayo Foundation
James M. Naessens, Gregory L. Angstman, Holly K. Kelley

INTRODUCTION

Breast cancer is one of the most frequent malignancies affecting women today. It is the most common cause of death due to cancer in females ages 40-50 (Eddy,1989). In 1991, the American Cancer Society estimated 175,000 new cases of invasive breast cancer diagnosed in females. The most important tools in the early detection of breast cancer are the clinical breast exam and screening mammography. Research indicates that mortality due to breast cancer can be reduced by 30% among women aged 50 and over through the use of these simple screening methods (Shapiro, 1977; Tabar, 1985). One study noted that the average sensitivity of the combined clinical examination and mammography over a five-year time period was 75% while the specificity of mammography approached 99%. (US Preventive Services Task Force, 1989). Yet the number of women receiving these preventive services remains alarmingly low. In the 1987 National Health Interview Survey Cancer Control Supplement, only 36% of women aged 40 and over had EVER received a clinical breast exam and screening mammography. For those women age 50 and older only 25% had reported having had a clinical breast exam and screening mammogram within the preceding 2 years (Public Health Service, 1990, page 429).

In 1990 the Public Health Service in Healthy People 2000: National Health Promotion and Disease Prevention Objectives established the goal of increasing to at least 80 percent the proportion of women aged 40 and older who have ever received a clinical breast examination and mammogram, and to at least 60 percent those aged 50 and older who have received them within the preceding 1 to 2 years. Since the Public Health Service established this goal, screening activities have increased to 64% of women over 40 reporting EVER having had a mammogram in 1990 (NCQA, 1993).

In an effort to improve the process for the evaluation of patients with breast disease, Mayo Clinic is currently implementing the breast cancer screening and diagnosis practice guidelines. These guidelines were developed with the Institute for Clinical Systems Integration (ICSI). ICSI was founded in 1993 through the joint efforts of the Mayo Clinic, Group Health, Park Nicollet Medical Center and HealthPartners as a response to the Business Health Care Action Group, a coalition of 24 Minnesota businesses. ICSI provides health care quality improvement services to 20 medical groups affiliated with HealthPartners in the Minnesota and Wisconsin region using continuous quality improvement principles to standardize health care processes and to improve health care outcomes. Health care guidelines represent a process for treatment or prevention of specific health conditions. The continuous quality improvement cycle is used to manage guideline development, implementation and improvement. To date, 26 guidelines have been approved for implementation by participating medical groups.

The first component in the breast cancer screening and diagnosis practice guidelines to be implemented in the primary care divisions at Mayo is the Primary Care Evaluation of the Breast (ICSI, 1995). This process starts with asymptomatic patients undergoing a screening examination, or symptomatic patients presenting with breast related complaints. The process ends when a diagnosis is established either by biopsy or by clinical and radiological findings. By reducing the variability of the evaluation process, we hope to improve the accuracy, timeliness and cost of care. With compliance, through increased screening mammography rates, we hope to identify breast cancer at its earliest possible stage and improve survival for patients with breast disease.

Performance and compliance with the guideline are assessed through standardized reporting measurements which have been defined in the development process. The measurement goals for the breast disease guidelines are to identify the stage of cancer at diagnosis and to accurately report screening rates.

The mammography screening intervals recommended by the guideline include: a monthly self breast examination beginning at age 30; a professional breast examination every 3 years for those aged 20-39 and annually for those aged 40-75. For those women with high risk for breast cancer, mammography is recommended annually beginning at age 40, with a baseline measurement done between the ages of 35-40. For those women at low risk, mammography is recommended annually beginning at age 50 and is optional for women age 40-49. A baseline measurement is recommended at age 40 for those women at low risk. Given the lack of consensus regarding the beneficial affect of screening mammography for women age 40-50 (Feig, 1994; Sickles, 1995; Smart, 1995), the breast mass guideline group considers the use of mammography to be OPTIONAL in this age group. Its use is left to the discretion of the primary care provider and the patient. Yearly mammography is appropriate for women in this age group found to be at high risk.

The basic principles and general guidelines for breast cancer screening defines the target population as women age 50-74 continuously enrolled in a health plan for twelve months. The three developed measures deal with mammography screening among all enrolled women; enrolled women who had a primary care visit; and enrolled women who had

a pelvic exam and pap smear or a complete physical examination.

In addition to screening rates, the guideline measures address outcome by examining the stage of cancer for all patients diagnosed. The basic principles and general guidelines for breast cancer diagnosis defines the target population as all newly diagnosed women with breast cancer through age 74. The two developed measures are defined as the proportion of early stage breast cancer at initial diagnosis (early stage is defined as stages 0,1 or 2.) and the percent of women at stage 2.

METHODS

We have evaluated baseline breast disease guideline measurements among patients served by seven sites within Mayo. Mayo Clinic is located in southeastern Minnesota in the city of Rochester. Although best known for its large referral and specialty practice, Mayo also has an extensive primary care practice. The seven sites evaluated include five primary care sections, the urgent care center and the specialty division of gynecology (GYN). The five primary care sections include two family practice sites: the Kasson Clinic and Rochester Family Practice; and three internal medicine sites: Area Medicine, Community Internal Medicine, and Preventive Medicine. The demographics of the patients each division serves varies as well as its location within the Mayo complex. All of the evaluated sites are located on the Mayo Rochester campus with the exception of the Kasson Clinic. The Kasson Clinic is a small clinic located 15 miles to the west of Rochester in Kasson, Minnesota. The Kasson Clinic serves mainly a rural population. The Preventive Medicine patient population is primarily Mayo Clinic employees. The Urgent Care Center is a walk-in clinic which targets patients with acute conditions, and is staffed by physicians from family practice and internal medicine on a rotating basis. The last group we examined is GYN. This division is staffed by specialists.

Mayo clinic has adapted the ICSI breast cancer screening guideline measurements to its fee-for-service practice using our 1993 billing files. However, not all of the measurements defined by ICSI were applicable in our setting. Since Mayo patients are not continuously enrolled in the system, all patients with Mayo services provided in the calendar year have been considered. Patient date of birth and gender have been extracted from the last Mayo registration in 1993. A patient's experience for the entire year was assessed. Therefore, the measurements from the breast cancer screening guideline have been adapted to the Mayo system and defined as mammography screening rates among women aged 50-74 with ANY service provided in the calendar year. The number of patients with a mammogram has been defined as any patient with CPT codes 76090-76092. The historical database does not identify the physician or division ordering services. Therefore, for the accompanying tables, a patient was assigned to each division where they were seen in the calendar year. In this way, an individual patient may be reported in one or several divisions. For a patient seen during the year in both the divisions of Family Practice and GYN, who had a mammogram ordered by GYN, Family Practice would also receive credit for this service. It is important to keep in mind that in our study the mammography rates are encounter based, not population based.

The guideline measurement for breast cancer diagnosis did not require modification to the Mayo system. Newly diagnosed cases of breast cancer at Mayo were identified through the cancer registry. American Joint Committee on Cancer (AJCC) criteria were used to assess the tumor stage at the time of diagnosis.

RESULTS

The baseline mammography screening rates for females ages 50-74 varied substantially across the practice groups from 49% in the rural family practice (Kasson Clinic) to 76% in Preventive Medicine (Table 1).
Not surprisingly, patients seen for preventive care or for pelvic examinations had higher mammography screening rates than those women who did not receive this preventive care in the calendar year. Overall, women who did not receive a general medical or pelvic exam, in the calendar year, had a screening rate of 40%, but the rate increased to 74% for those women with these preventive services. The screening rates among women with preventive exams ranged from 66-81%, while the rates for women without these services ranged from 22-55%. Much of the higher rates for Preventive Medicine and Area Medicine is explained by the predominance of patients with pelvic and general exams. The higher proportion of acute care patients in the Urgent Care Center and the rural family practice (Kasson Clinic) resulted in lower overall mammography rates.

Since Medicare reimbursement for a mammogram is every 2 years, it was anticipated that the mammography rate may be lower for those women over age 65 in our fee-for-service practice. However, this was not the case. Overall screening rates varied only slightly by age, 65% for those age 50-54, 67% for those age 55-59, 66% for those age 60-64, 67% for those age 65-69 and 62% for those age 70-74 (Figure 1).

In addition to screening rates, the guideline measures address outcome by examining the stage of cancer for all patients diagnosed. In 1993 there were 399 newly diagnosed cases of breast cancer at Mayo among women. Ages ranged from 29-94. Ninety-one percent were diagnosed in an early stage (stage 0-2) (table 2). The ICSI defined measurements include only those through age 74. Excluding those age 75 and older the overall rate of those diagnosed in early stage is 89%. Given the considerable controversy surrounding the beneficial effects of screening mammography for women age 40-49, we

Table 1: 1993 Rates by Division for Females Ages 50-74

	Mammography Screening Rates (%)			Preventive Care (%)
	Overall	- Preventive Care	+ Preventive Care	Overall
Rural Family Practice	49	27	66	57
Rochester Family Practice	65	38	76	73
Community Internal Med	74	54	81	75
Area	73	41	78	87
Preventive	76	45	81	86
Urgent Care Center	53	22	72	63
OB/GYN	67	55	69	80
Overall	65	40	74	--

Figure 1: Population vs Fee-For-Service Mammography Screening Rates, 1993

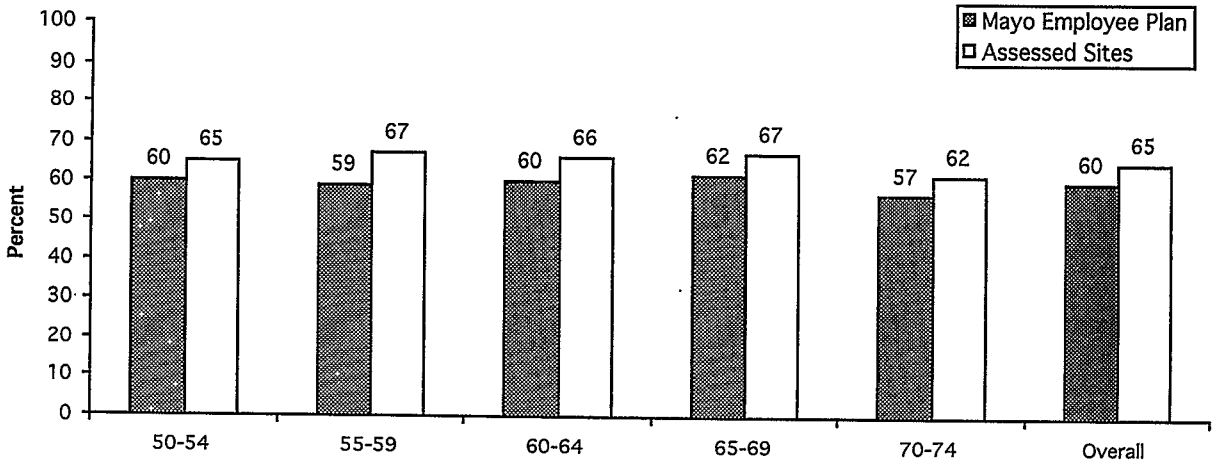

Table 2: Women Diagnosed at Mayo With Breast Cancer, 1993

	All Women				Those at Assessed Sites			
		Stage (%)				Stage (%)		
	N	0-2	2	Lymph node involvement %	N	0-2	2	Lymph node involvement %
<40	9	89	33	11	7	86	43	14
40-49	43	86	44	37	14	79	36	50
50-74	256	90	29	25	103	96	29	24
75+	91	96	29	17	35	94	31	23
Overall	399	91	30	24	159	94	31	26

have looked at this data in the following age groups; <40, 40-49, 50-74, and 75+. The percent of those women diagnosed in an early stage was somewhat stable across these age groupings, ranging from 86% for those aged 40-49 to 96% for those aged 75 and older. The percent of these patients with stage 2 breast cancer and lymph node involvement at the time of diagnosis were more varied across the age range. Forty-four percent of those patients aged 40-49 compared with about 30% for the other age groups were diagnosed at stage 2. Those patients ages 40-49 also had a higher percentage of patients with lymph node involvement at the time of diagnosis (37%). Overall 24% of all newly diagnosed cases of breast cancer had some lymph node involvement at the time of diagnosis.

Examining all cancers newly diagnosed at Mayo, we include many patients who have been referred to us for specialty care. It should be noted that 61% of those patients with a breast cancer diagnosis in 1993 did not have a patient encounter with the reported divisions at Mayo in this calendar year. When including only those women seen at the sites analyzed, 94% were diagnosed at an early stage. This rate did not change when we excluded those aged 75 and older. The percent of stage 2 and lymph node involvement in these patients were similarly affected by a small percent (Table 2).

DISCUSSION

The data presented here reflects practice prior to guideline implementation. In comparison with data in the literature it needs to be stressed that our rates are encounter-based and not population-based. Also, the data includes only those mammograms done at Mayo. Similarly, in considering the mammography rates for those women with general medical or pelvic exams the preventive services are captured only if the exam was performed at Mayo. Any mammogram, general medical or pelvic exams done outside of the Mayo system are not reflected in these percentages. As expected, the urgent care center is affected more by this limitation in the data than some of the other divisions due to a higher likelihood of these patients having received medical care at a facility other than the Mayo Clinic.

To assess the comparability to population-based rates, mammography screening rates have also been calculated for a defined population of females between the ages of 50-74 who are enrolled in the Mayo Employee health plan during the 1993 calendar year. This plan includes all employees, retirees, and eligible spouses and dependents of Mayo employees. This population has better access and coverage than the general population, but may be similar to other health plans in the Midwest. The overall baseline screening rate in 1993 for this population was 60% (figure 1). The comparison of rates for each age group with those for all patients seen is also displayed. The screening rates for the defined population was slightly lower than the encounter based rates across all age groups. Approximately 6% of the women overlap between the encounter-based data and the defined population of the Mayo Employee Health plan.

To date, the breast disease guidelines have been implemented in four of the primary care divisions. The rural family practice located in Kasson began implementation in October of 1994. The divisions of Area Medicine, Community Internal Medicine and Rochester Family Practice implemented these guidelines during 1st quarter of 1995. There has been a mixed reaction to the guidelines by physicians within the primary care divisions. The initial reaction is to assume that the current practice is already following the guideline recommendations. After reviewing the baseline numbers specific to their division they are much more receptive to the guideline and implementation efforts taking place. To date, the four groups are focusing on different aspects of reducing barriers and inefficiencies in their current process. Potential access limitations with efforts to increase the patient demand for services have also been raised. It is still too early to assess the results of the implementation efforts, since this data is not yet available.

In conclusion, there are four main issues raised in our study:

1. Measuring compliance with guidelines needs to address issues within control of the implementation team and must be clinically relevant. Measures developed by Health plans (i.e. HEDIS) may need modification for use by a fee-for-service clinic.
2. Variability of performance suggests that room for improvement exists even among high quality providers.
3. Practitioner group specific mammography rates provide a useful basis for the identification of specific barriers and lead to further understanding of issues in the delivery of health care.
4. The appropriateness of mammography screening among 40-49 year old females is still unsettled. Guidelines and their measurements need to be continuously adapted to changes in the "best practice" of medicine.

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MORTALITY OF FEMALE BREST CANCER IN NORTH RHINE-WESTPHALIA, 1980 - 1993,

Doris Bardehle,State Institute for Public Health, North Rhine-Westphalia, Germany
Rolf Annuß

Summary

Breast cancer takes the highest mortality rate among women aged 35-64 years in the European Community. In Germany, the mortality rates of female breast cancer could not be reduced during the eighties. Detailed regional analyses were not carried out systematically. An overall cancer register does not exist.

In North Rhine-Westphalia, with 17 million inhabitants the largest of the 16 states in Germany, the mortality rates of female breast cancer in the age group from 35 - 64 years amounted to 46.2 per 100,000 females in 1980 and remained unchanged up to 1993 with a mortality rate of 46.5. The data are standardized to the „new" European population.

An analysis of the 54 counties of North Rhine-Westphalia shows differences among the regions, but only one region, the county of Aachen, shows significantly deviating rates below the average. Another analysis shows the trend in breast cancer mortality rates by 5-year age groups ≥ 15 years.

The second of the proposed 10 health objectives for North Rhine-Westphalia relates to cancer control. Indicators like mortality rates (among them avoidable cancer mortality up to 65 years of age), incidence rates, (among them age-specific incidence rates of female breast cancer), coverage rates for early cancer detection programs and additional indicators of the effectiveness of early detection programs and treatment (inpatient morbidity, inability to work) are analysed.

Introduction

In the latest edition of the "Europa-Blätter about Health" [Euroblätter Nr. 2/95, March/April (14)] an analysis of the mortality statistics on the level of the European Commity and World Health Organization was published. The dominant cause of death for women, aged 35-39 years and 40-64 years was breast cancer. We all must be worried about this and analyse the situation.

Latest literature about trends in incidence and mortality of female breast cancer does not give important new information. I will try to give a short survey about the situation in different European countries and in the USA and compare these data with German data - analysed for North Rhine-Westphalia, with 17 million inhabitants the largest of the 16 German states.

In Sweden the reduction of mortality of breast cancer is put down to a permanent risk reduction associated with screening in all analysed 5 studies carried out with 282,777 women who were followed up in randomised trials over a period of 5-13 years.

The largest reduction of breast cancer mortality (29 %) was observed among women aged 50 - 69 years at randomisation. Among 40 - 49-year-old women there was a non-significant 13 % reduction [Nystroem, L. et al., (1)] Among 70 - 74 year-old-women screening seems to have had only a marginal impact.

The National Center for Health Statistics (USA) analysed temporal trends in breast cancer mortality among US women who were examined from 1969 through to 1989 by age, race and county-level socioeconomic status. The mortality ratio in counties with a high - relative - to low socioeconomic status declined significantly among women. A relative increase in breast cancer incidence could be registered in counties with a lower socioeconomic status. [Wagener, DK.; Schatzkin, A (4)].

The National Cancer Institute [Glass, AG.; Hoover RN.,(2)] analysed breast cancer incidence from 1960 to 1985. The incidence rate rose by 45 % during this period. The largest increases occured among 60-year-old or older women, (74 %) and among 45 - 69-year-old-women (36 %).

Sondik (NCHS, USA) described a steady increase in the rate of breast cancer cases since 1950, with a sharp rise in the 1980s because of the increased use of mammography. Conversely, mortality since 1973 had declined by 11 % for women younger than 50 (the decrease occurred primarily in the 70s) and increased by 6 % for women aged 50 and older [Sondik, EJ., (5)].

In 1994 Kopans (USA) [Kopans, DB, (6)] published in the Journal of the American Cancer Society, that in 5 of the analysed 8 randomized trials, controlled trials have demonstrated a mortality reduction for screened women that ranges between 22 % and 49 %. He concluded, that the recent withdrawal of screening support for 40- to 49-year-old-women is not scientifically supported. But other studies show that there is no difference in survival for 40-49-year-old women and/or for 50-59-year-old women.

This corresponds to findings by Garfinkel, Boring, Heath [Garfinkel, L. et al.(7)], that the increase in breast cancer incidence coincides with an increased use of mammography in asymptomatic women in the 1980s. Mortality from breast cancer has changed little since the 1930s, but the increases in localized and small-size tumors and decreases in the rate of tumors of 3 cm or larger at diagnosis indicate that breast cancer mortality may start to decrease.

After analysing a group of women enrolled in the Mamma Breast Self-Examination Program, Gastrin et al. (Finland) [Gastrin, G., (8)] concluded that the reduction in mortality from breast cancer in the study group is consistent with an effect of the Breast-Self-Examination-containing Mamma Program.

For the former German Democratic Republic Ebeling reported an annual mamma carcinoma incidence rate of 60 per 100,000 women [Ebeling, K., (3)]. Latest figures provided by the cancer registry for the new federal states [(M. Möhner et al. (12)] (former GDR) assume a rough incidence rate of 72 diseases per 100,000 women by the year 1989. In 1973 already, Bardehle [D. Klessen (Bardehle, 13)] calculated a rough incidence rate of 72 diseases per 100,000 women for East Berlin, a rate which at that time was by 30 % higher than the average rate for the GDR.

As to the old Federal States the incidence rate, based on the cancer registry of the Saarland corresponds to 87.5 diseases per 100,000 women with a mortality rate of 37.9 per 100,000 women (age standardized rates for the population of the Federal Republic of Germany of the year 1987) [B. Pesch et al.; Krebsatlas Nordrhein-West-

falen (11,)]. The incidence rates of the cancer registry Münster for a part of the State North-rhine-Westphalia in 1989 amounted to 60 and rose to 70 in 1992.
(Standardization for old European population).

Breast Cancer Mortality in North Rhine-Westphalia (NRW)

Publications about Years of Potential Life Lost (YPLL) in the United States and calculations for North Rhine-Westphalia with the same method show an elevated level for all causes of death in the United States, but in the field of cancer the years of potential life lost are higher in North Rhine-Westphalia. Therefore it would be important to analyse mortality rates of female breast cancer for Germany and for the United States of America (table 1).

For comparing breast cancer mortality between the USA and North Rhine-Westphalia over the years 1980 to 1993 the „new" European standard population was used, a population created by the UN on the basis of the population cross-section of all European states of the year 1991 (table 2). Since, compared with this standard population, the female German population is older, many of the standardized figures, which are related to diseases occuring more frequently at a higher age, will be lower than the socalled „rough" non-standardized rates. Standardization of mortality rates due to breast cancer in the United States led to following results:

The rates for NRW which includes all age groups shows following deviations (figure 1):

In North Rhine-Westphalia, the mortality rates due to female breast cancer, related to all age groups and standardized with regard to the „new" European population rose from 38.6 in 1980 to 40.4 in 1993. This corresponds to a slightly positive linear trend with the data:

$F(t) = 37{,}79 + 0{,}21\ (t)$ corr. coeff. $r = 0{,}70$
standard deviation 1,24

Trend 1980 - 1993 by Age Groups, NRW

As to North Rhine-Westphalia, breast cancer mortality was analysed with respect to various criteria, e.g. for 35-64 year-old women, for 25-64-year-old women, for women according to 5-year-age groups and for all women within temporal trends.

For the 35-64-year-old women mortality rates for the years 1980 to 1993 were calculated for all counties and the State North Rhine-Westphalia. A comparison of age standardized rates shows that, apart from minor deviations, the mortality rate of 46.2 per 100,000 of the 35-64 year-old women from the year 1980 did not change up to 1993, in which the mortality rate amounted to 46.5 per 100,000 of the 35-64 year-old women. An assessment of these figures which remained about unchanged requires a comparison with the incidence rates which are available from 1987 up to 1992 for a part of the State North Rhine-Westphalia. In this context of increasing incidence rates and unchanged mortality rates due to breast cancer the unchanged trend of mortality rates alltogether does not represent an unfavourable development (figure 2).

For a more detailed evaluation of breast cancer for the years 1980 - 1993 linear trend functions for the 5-year-age groups from 25-29 years up to 85 years and older were calculated and shown in a diagram (figure 3) . The following is noticeable: In each of the following 5-year-age groups mortality is higher than in the preceeding one. Hence, the 25-29-year-old represent the lowest mortality rate, the 85-year old and older women the highest. The correlation coefficient for the lowest age groups is negative, while with increasing age the positive value of the correlation coefficient rises. The increase in mortality starts above all with the 65-year-old and older women. The diagramm becomes clear when for the average figures of the years 1980 to 1982 the value „100" is chosen for all age groups and the mortality trend of the average death rates up to the years 1991 - 1993 is shown (figure 4). It is clearly recognizable that the mortality rate of the younger age groups could be reduced, but that on the other hand the mortality rate of the 65-year-old and older women rose by 10 to 20 %. Hence the unchanged mortality rate for all age groups conceals a considerable differentiation when analysing mortality by 5-year-age groups.

Regional Differences

North Rhine-Westphalia is subdivided into 54 counties and independent municipalities with a population of at least 200,000 inhabitants on average. For a comparison by regions for the years 1980 - 1993 mortality, due to the low figures, was not only calculated for all counties according to individual years, but in addition an age standardization was carried out for all 14 years that were taken as a basis (in accordance with the „new" European population). The 35-64-year-old women represent the so-called „truncated population", which in North Rhine-Westphalia over the 14 years amounts to an average mortality rate of 46.7 per 100,000 women of the respective age group (standardized to the „new" European population) (figure 5). The highest average figure is shown by the county of Herne with a mortality rate of 54.8 per 100,000 of the 35-64-year-old women (age standardized), the lowest figure by the county of Paderborn with a mortality rate of 38.6 per 100,000 of the 35-64-year-old women (age standardized).

Avoidable Mortality

According to the proposals by a working group of the European Union "avoidable cases of death" include those which are meant to stand for effectiveness and quality of health care, e.g. within the framework of early recognition programs or successful early treatment. On the other hand those cases of death are excluded which are caused by negligence or culpable failure of individual persons. At present mortality is restricted to 12 causes which showed significant differences among the regions when an analysis was carried out in one state of the Federal Republic of Germany (Rhineland-Palatinate). This includes female breast cancer of women, aged 25-64 years.

On this methodical basis the Standardized Mortality Ratio (SMR) for the years 1989-1993 was calculated for the 25-64-year-old women who died as a consequence of breast cancer within these five years (figure 6). In addition the figure was checked with the confidence interval. The restriction to this age group was made because for the under 65-year-old women epidemiological changes above all in relation to the reduction of mortality rates became obvious. The SMR was related to the mean of the State North Rhine-Westphalia for the observation period 1989 - 1993. Accordingly, the SMR takes the value 1.0 if the Specific mortality rate in one county exactly corresponds to the state average. Within the 54 counties the SMR ranges between 0.67 and 1.21. In

this connection no county shows a significantly elevated sMR, two counties are significantly below the state average (significance calculated using 95 per cent confidence intervals).

The Epidemiological Situation of Female Breast Cancer

Incidence of the Mamma Carcinoma 1987 - 1992, Cancer Registry Münster

For 10 years the cancer registry in Münster has been registering the incidences of all malignant tumors for a residential area of 2.3 million inhabitants of the State North Rhine-Westphalia. The registrations are 80-85 % complete. The incidence rates, standardized to the „old" European population, show an increase from 60 to 70 per 100,000 of the female population from the years 1987 to 1992 (figure 7).

Trend observations of incidence as well as mortality rates by 5-year age groups lead to following conclusions for the years 1987 to 1992:

Above all among the 40 to 64-year-old women the incidence rates rose by following values: related to 100,000 women of the respective age group:

age group	1987	1992
40-44 years	55.3	83.5
45-49 years	92.0	130.4
50-54 years	115.3	160.9
55-59 years	130.1	160.4
60-64 years	143.4	168.4

Over this period from 1987 to 1992 mortality rates per 100,000 women for the same age groups developed as follows:

age group	1987	1992
40-44 years	23.4	30.7
45-49 years	45.1	36.8
50-54 years	56.3	57.1
55-59 years	74.1	77.4
60-64 years	81.1	85.3

Interpretation: The quotient of the women who fell ill in 1987 and died on average was 2:1 in favour of the incidences. In 1992 a higher incidence rate was registered for all age groups and a ratio between incidence and mortality which for the younger age groups amounted to 3:1 in favour of the incidences. As to the 50-54-year-old women, the absolute figures of the women suffering from breast cancer within the county of Münster in 1987 amounted to 91, in 1992 to 137 women. It cannot be excluded, that variations are due to low figures and that the registration quota may be different. The trend of increasing incidence rates with relatively unchanged mortality rates as described in literature is however comprehensible.

For characterizing the epidemiological situation, incidence rates (source: Federal AOK Association), the rate of patients treated in hospitals (source: ditto), the rate of patients unable to work (source: ditto) and mortality rates (source: State Office for Data Processing and Statistics for the State North Rhine-Westphalia) are shown (figure 8). It is clearly recognizable that all four indicators mentioned show one break at the age between 45 and 69 years, hence underline the double peak character of the disease. The rate of women treated in hospitals represents the highest figures, at old age treatment rates decrease - as we all know - incidence rates increase and mortality rates strongly increase. Inability to work abruptly stops as soon as these women enter their retirement age. This is how the situation in terms of epidemiology and treatment in North Rhine-Westphalia can be described.

Early Detection of Cancer - Programs and Results in NRW

In 1971 the statutory program for early detection of cancer was introduced in the Federal Republic of Germany and has been modified several times. [Krankheitsfrüherkennung Krebs, (9)].

At present it includes following examinations for women:

from the age of 20 up: examination for cancer of the genitals
from the age of 30 up: in addition examinations for breast and skin cancer
from the age of 45 up: in addition examinations for cancer of the rectum and colon

The program for early detection of breast cancer includes breast palpation and instructing women on self-examination of the breast. Mammography is considered a method of diagnostic clarification and is not part of the program for early detection of cancer. According to our information about 3.3 million women of the State NRW annually take part in the examinations, related to all types of cancer mentioned in the program.

The age standardized discovery rates of breast cancer varied considerably between the two regions of Westphalia-Lippe and North Rhine and at first examinations in Westphalia-Lippe amounted to about 100 discovered mamma carcinomas per 100,000 women examined for the first time and to about 55 discovered mamma carcinomas per 100,000 examined women (first and repeated examinations at different intervals). In North Rhine, with about 20 - 25 discovered mamma carcinomas per 100,000 of the women examined for the first time and about 15 mamma carcinomas per 100,000 of the repeatedly examined women (first and repeated examinations), these rates differed considerably and were below the average of the whole Federal Republic of Germany. The rate of the non-confirmed diagnoses amounted to about 90 %, the confirmed diagnoses to about 3 %, the remaining 7 % cannot be determined. The hence calculated discovery rate for the Federal Republic of Germany in 1990 amounted to 41 breast cancer incidences per 100,000 examined women aged 30 or older, whereas in 1989 96 mamma carcinomas per 100,000 women aged 30 or older were discovered. These varia-tions between the regions in North Rhine-Westphalia and between the results of the years 1989 and 1990 show how difficult an evaluation of data for a whole state is, data which are based on a participation rate of annually over 30 % of the entitled female population [Bernt-Peter Robra, Evaluation des deutschen Krebsfrüherkennungsprogramms, (10)]

Conclusions:

The G7 summit in Brussels in February 1995 with the member states Canada, France, Germany, Italy, Japan, United Kingdom, USA, and with the European Commission and WHO set up a global telematics programme to facilitate access to the relevant public health knowledge bases in the G7 member states: to be prepared by the end of 1996. Two sectors have been selected for testing: communicable diseases and vital statistics to be extended to health indicators next. To prove the validity of one's own data like in the field of breast cancer, availability of data and their

comparison with US data will be one step in the direction of a G7 telematics information system.

The problem of high rates of breast cancer mortality could be an important health indicator for evaluating the effectiveness of early detection programs. The exchange of data with the help of telecommunication technology and providing the means for a comparability of data among the mentioned 7 states could be a very attractive task for all of us.

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Table 1:

Years of Potential Life Lost, YPLL

Years lost per 100 000 population under 65 years of age

Causes of Death	USA, 1991		NRW, 1993	
All causes	5556	100 %	3463	100 %
Cancer	843	15,2 %	1023	29,5 % ICD 140 - 208
Heart disease and stroke	737	13,3 %	656	19,0 % ICD 390 - 436 (401, 403 excl.)
Intentional and unintent. injuries	1637	29,5 %	600	17,3 % ICD 800 - 999
HIV / AIDS	347	6,3 %	69	2,0 % ICD 42 - 44

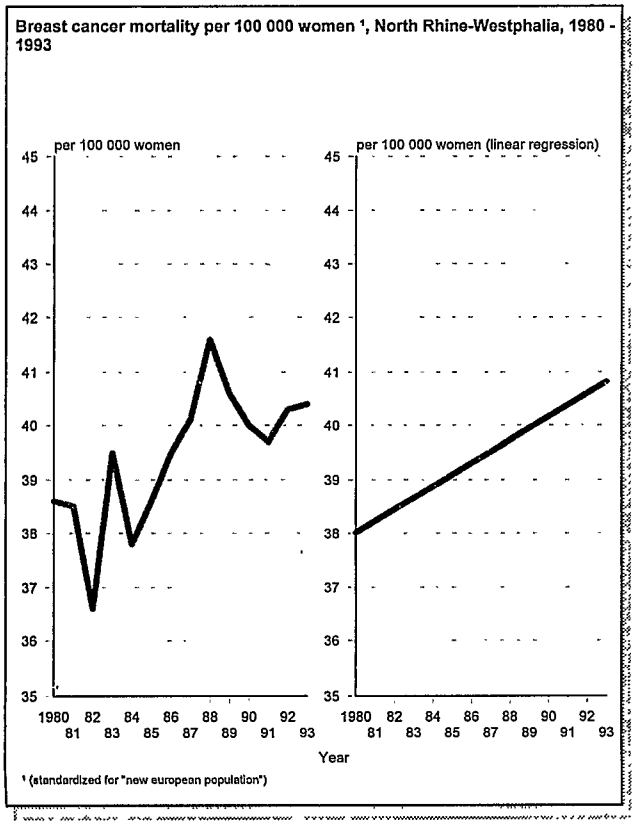
Source: CDC, National Center for health Statistics, U.S.A.
State Institute for Public Health, North Rhine-Westphalia

Table 2:

"Old" and "New" European Standard Population by age groups and sex

age groups	"Old" European Population 1966	"New" European Population 1991		
		total	of which male	of which female
0 - 1	1.600	1.305	1.345	1.218
1 - 4	6.400	5.021	5.303	4.800
5 - 9	7.000	6.472	6.800	6.160
10 - 14	7.000	6.772	7.108	6.452
15 - 19	7.000	7.208	7.570	6.863
20 - 24	7.000	7.792	8.163	7.438
25 - 29	7.000	7.871	8.206	7.552
30 - 34	7.000	7.528	7.811	7.258
35 -39	7.000	7.212	7.448	6.986
40 - 44	7.000	6.860	7.168	6.661
45 - 49	7.000	5.865	5.997	5.739
50 - 54	7.000	5.876	5.937	5.817
55 - 59	6.000	5.553	5.521	5.585
60 - 64	5.000	5.245	5.015	5.463
65 - 69	4.000	4.680	4.139	5.196
70 - 74	3.000	2.932	2.449	3.392
75 - 79	2.000	2.897	2.228	3.536
80 - 84	1.000	1.606	1.094	2.076
85 +	1.000	1.305	798	1.808
Total	100.000	100.000	100.000	100.000

Figure 1:



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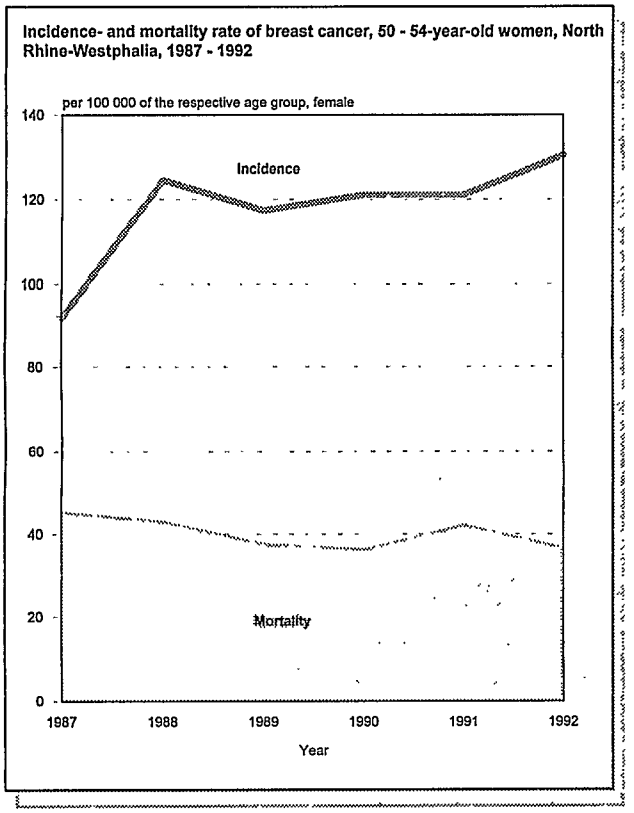

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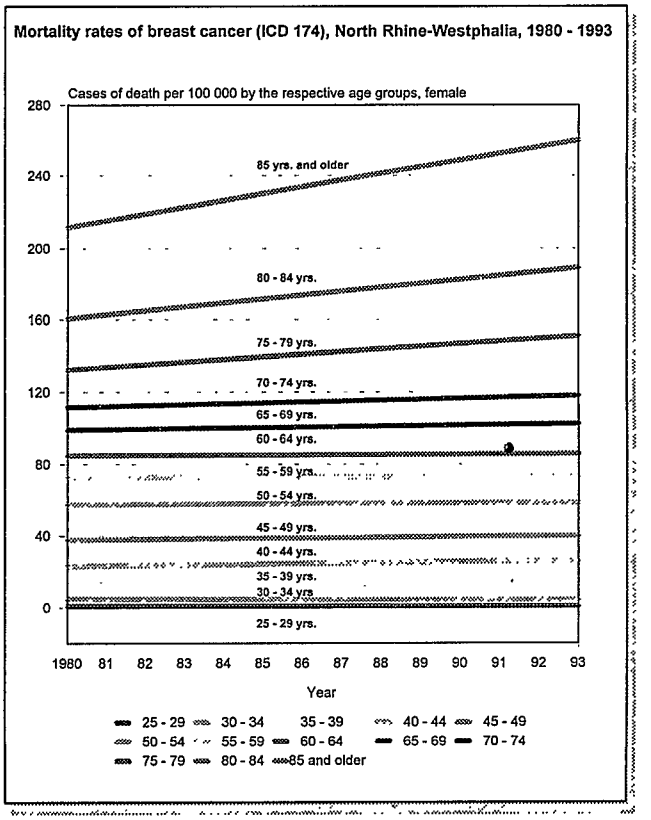

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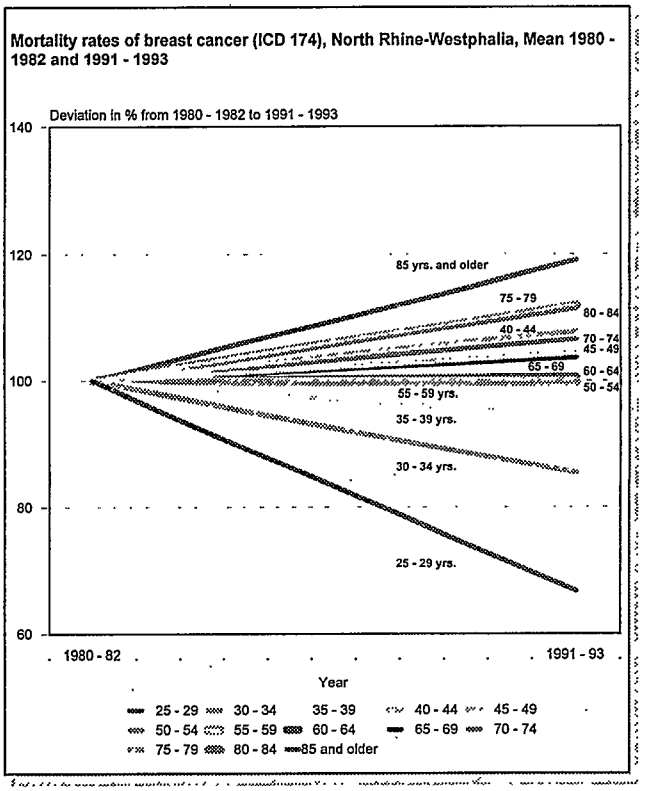

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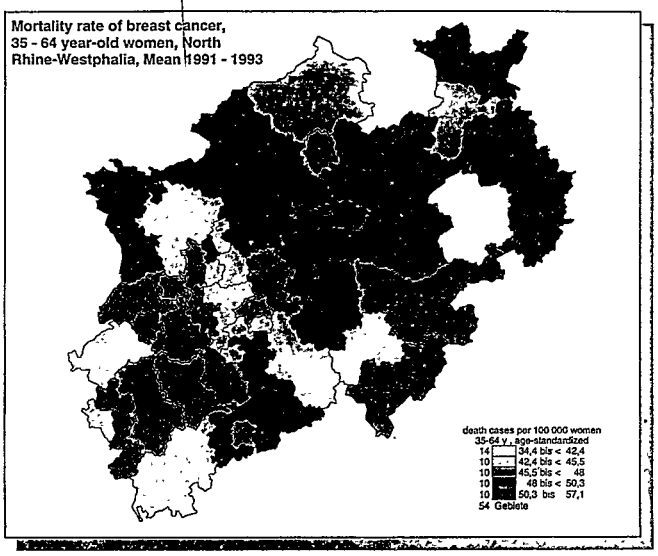

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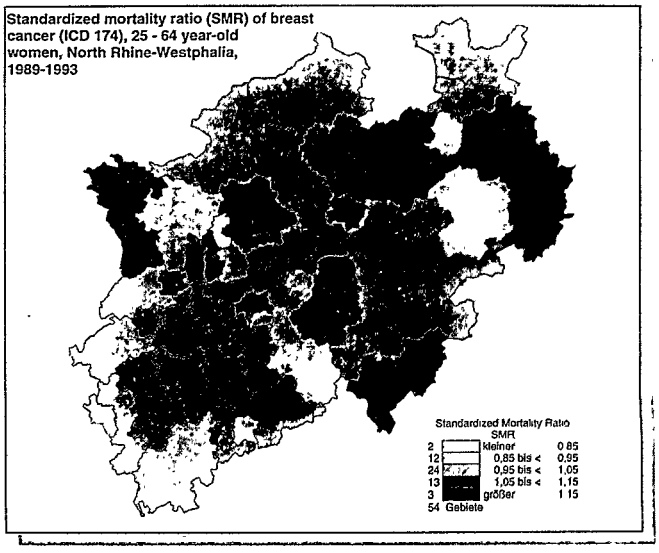

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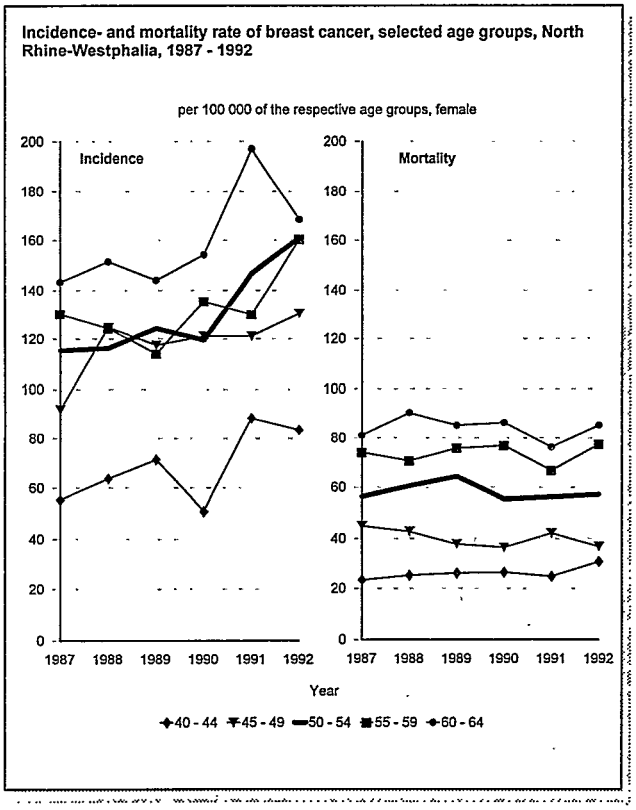

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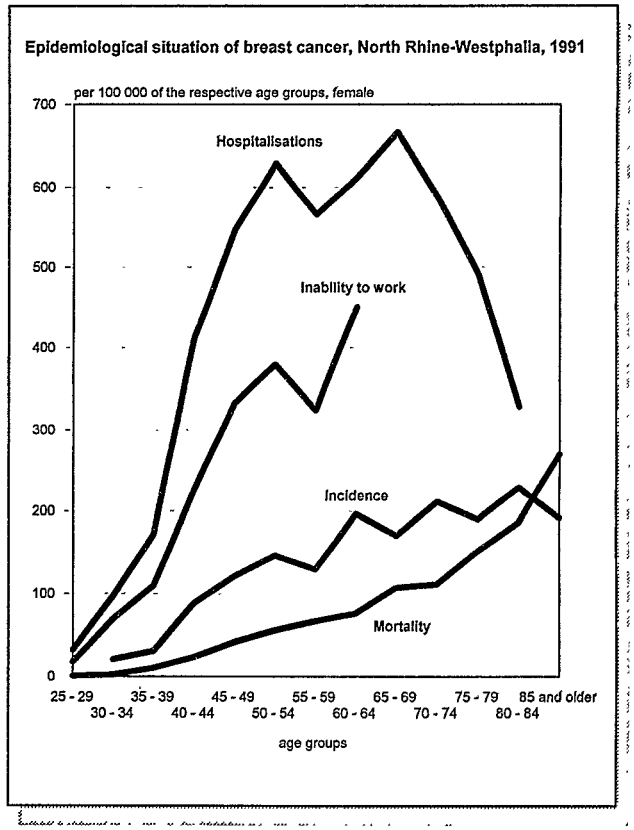
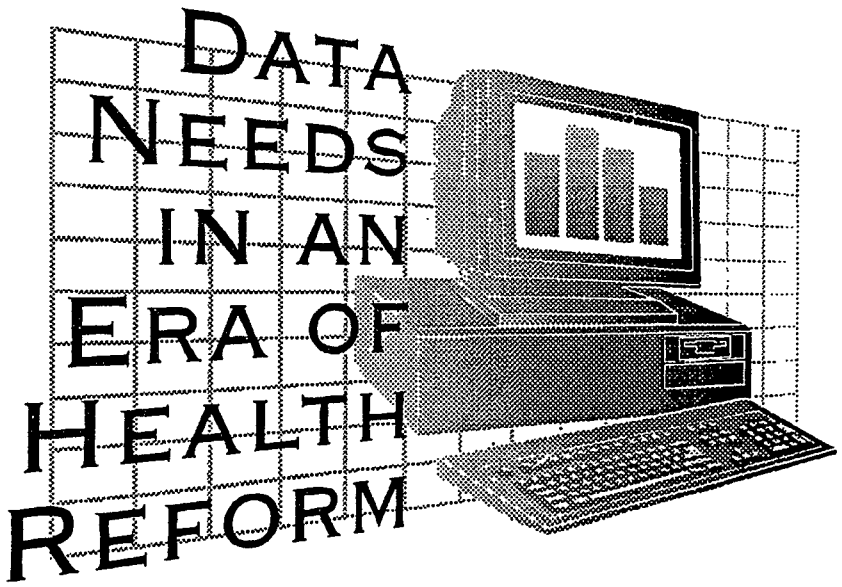


Second Plenary Session

The Potential of Health Reform for Vulnerable Populations: A Challenge for Public Health



AT RISK IN AMERICA: HEALTH AND HEALTH CARE FOR VULNERABLE POPULATIONS

Lu Ann Aday, The University of Texas School of Public Health

WHO ARE THE VULNERABLE?

Vulnerable individuals are "susceptible to harm or neglect". The word "vulnerable" is derived from the Latin verb "vulnerare" ("to wound") and the noun "vulnus" ("wound")(Aday, 1993).

"Vulnerable populations are **at risk of poor** physical, psychological, or social **health.**"

Health can be measured along a continuum of seriousness with good health being at the positive end of the continuum, defined by the World Health Organization (WHO) concept of health as a "state of complete physical, mental, and social well-being..." (World Health Organization, 1948, p. 1), and death at the negative end, as the total absence of health, defined by population-specific mortality (death) rates.

Underlying this definition of vulnerability is the epidemiological concept of risk, in the sense that there is a probability that an individual will become ill within a stated period of time. Given this sense of the notion of risk, we are all vulnerable, that is, there is always a chance (or a non-zero probability) that we will become ill at some time in our lives.

Vulnerable populations may be identified based on those for whom the risk of poor physical, psychological or social health has or is quite likely to become a reality:

physical: high-risk mothers and infants, chronically ill and disabled, persons with AIDs;

mental: mentally ill and disabled, alcohol or substance abusers, suicide- or homicide-prone; and

social: abusing families, the homeless, and immigrants and refugees.

There is, of course, overlap among these groups, and the boundaries should be viewed to be diffuse rather than distinct.

Poor health along one dimension (physical) is quite likely to be compounded with poor health along others (psychological and/or social, for example). Health needs are greatest for those who have problems along more than one of these dimensions.

WHY ARE THEY VULNERABLE?

Two different mother tongues -- those of "individual rights" and the "common good" -- have historically characterized American social and political discourse. The semantics of the first emphasize the meanings of autonomy, independence, and individual well-being, while the second highlights norms of reciprocity, interdependence, and the public good. Robert Bellah, et al. (1985) and others (Beauchamp, 1988; Tesh, 1988) have, however, observed that in contemporary American society, the first language of individualism has come to override the second mother tongue of community. Excessive individualism may, he argues, be "destroying those social integuments [ties] that de Tocqueville saw as moderating its more destructive potentialities" (Bellah, et al., 1985: viii).

James Coleman (1990), in his book, Foundations of Social Theory, points out that to formulate meaningful theories or explanations of social phenomenon, both the macro (collective) as well as micro (individual) levels of observation and analysis and their interrelationships must be examined. Focusing on individuals' characteristics, attitudes or behaviors (violence-proneness) may fail to reveal the impact that larger social influences or trends (media violence and associated societal tolerances of violence toward women and children) have upon the individuals themselves. Correspondingly, theories regarding relationships between largely collective phenomenon (the prevalence of media violence and rates of violent crime) that fail to illuminate the dynamics of these social forces for individuals fall short of developing fully meaningful explanations of the phenomenon. The measurement of collective phenomena at the individual level of analysis (methodological individualism) also tends to bias the explanations of these phenomena toward individual motivations and actions.

Ethical Norms and Values

An individual perspective on the origins of poor health views personal autonomy, independence and associated individual rights as the principal ethical norms and values for guiding decision-making regarding the amelioration of risk. Good health is

viewed to be primarily a function of personal lifestyle choices, and poor health outcomes result because individuals fail to assume adequate personal responsibility for their health and well-being.

A community perspective on the origins of health needs focuses on the differential risks that exist for different groups as a function of the availability of opportunities and resources for maximizing their health. Norms of reciprocity, trust and social obligation acknowledge the webs of interdependence and mutual support and caring that are essential for minimizing the risks of poor health. Poor health results because communities fail to invest in and assume responsibility for the collective well-being of their members.

Needs Assessments

Individual health needs assessments measure the health status of identifiable community residents or patients (based on symptoms or diagnoses of illness, for example).

Community health needs assessments focus on statistical indicators of the rates of prevalence or incidence of morbidity or mortality (such as infant mortality rates, HIV-seroprevalence, percent of the elderly with limitations in activities of daily living, and so on).

The former has principally been the focus of personal medical care service delivery and practice and the latter of public health policy and planning.

Relative Risk

Relative risk refers to the differential vulnerability of different groups to poor health. People may be more or less at-risk of poor health at different times in their lives, while some individuals and groups are apt to be more at-risk than others at any given point in time.

The beginning point for understanding the factors that increase the risk of poor health originates in a macro-level look at the availability and distribution of community resources. Individuals' risks vary as a function of the opportunities and material and nonmaterial resources associated with (1) the personal characteristics (age, sex, and race/ethnicity) of the individuals themselves; (2) the nature of the ties between them (family members, friends, and neighbors, for example); and (3) the schools, jobs, incomes and housing that characterize the neighborhoods in which they live.

Social status is associated with positions individuals occupy in society as a function of age, sex, or race/ethnicity, and the corollary socially defined opportunities and rewards, such as prestige and power, they have as a result.

Joel Kovel (1984) in his book, White Racism: A Psychohistory, distinguishes dominative, aversive, and meta-racism. Dominative racism involves enslavement or other forms of forced labor, which characterized the first two centuries of African-Americans' experience in the United States. Aversive racism is a racism of avoidance and separation, enforced, for example, by the "separate but equal" provisions and Jim Crow laws that continued to direct race relations into the first half of this century. Metaracism refers to a muting of the overt rhetoric regarding racial superiority, and the sustained dominance of a pervasive, white-majority control of the economy, politics and cultural standards of truth and beauty, that characterize contemporary U.S. society.

These "-isms" may also be applied in characterizing the treatment of women historically and contemporarily: as largely enslaved by patriarchal social and economic systems of dominance to the exclusion of women from the right to vote or the workplace to the pervasive and insidious forms of oppression and marginalization reflected in sexual stereotyping, the misogynist portrayal of women in the media, and the social and economic de-valuing of the roles they play in the home and the marketplace.

Social capital resides in the quantity and quality of interpersonal ties between people. Families provide social capital to members in the form of social networks and support and associated feelings of belonging, psychological well-being and self-esteem. The value of social capital to individuals (single mothers) is that it provides resources (such as having someone to count on for child care) they can use to achieve other interests (going to school or working).

Social support has been found to be an important resource for individuals in coping with and minimizing the impact of negative life events or adversity on their physical and mental health. Physical, psychological, and social well-being are directly enhanced for people who have supportive social

networks. Communities constitute the reservoir in which social capital resources are both generated and drawn upon by individual community members. Those who are likely to have the least social capital (or the fewest social ties to count on) are people living alone or those in female-headed families, those who are not married or in an otherwise committed intimate relationship, people who do not belong to any voluntary organizations (such as churches or volunteer interest groups), or have weak or nonexistent social networks of family or friends.

Human capital refers to investments in people's skills and capabilities (such as vocational or public education) that enable them to act in new ways (master a trade) or enhance their contributions to society (enter the labor force). Social capital can also enhance the generation of human capital through, for example, family and community support for encouraging students to stay in school. Neighborhoods that have poor schools, high rates of unemployment and substandard housing reflect low levels of investments in the human capital (or productive potential) of the people who live there. Similarly, individuals who are poorly educated, unemployed and poorly housed are likely to have the fewest resources for coping with illness or other personal or economic adversities.

WHO IS MOST VULNERABLE?

Those individuals with a combination of statuses (poor, elderly women, those living alone, or minority adolescents) that put them at a high risk of having both poor health and few material and nonmaterial resources are in a highly vulnerable position.

The 1990s have been and promise to continue to be a harmful, not a kind and gentle, decade for many vulnerable Americans.

WHAT DATA PROBLEMS EXIST?

Ambiguity of Definitions

A fundamental problem in identifying who and how many are vulnerable is ambiguity in the definitions of the vulnerable populations themselves.

High-risk mothers and infants have been identified using a variety of predictors and indicators of both morbidity and mortality (such as low or very low birthweight infants and maternal and infant deaths). The chronically ill and disabled have been defined based on diagnoses, disability, and functional status, as well as quality of life measures. The case definition of AIDS has been revised three times since it was first published in 1982. At least four generations of studies in the mental health field can be identified in this century, all of which used either different approaches or instruments (record sources and key informants, psychiatric clinical judgments, standardized surveys, and measures of social functioning), for defining cases of mental illness.

The measurement of alcohol or substance abuse is made more difficult by the fact that there are different stages in the development of the addictive behaviors: nonaddictive use, excessive use (abuse), addictive dependency, and recovery or relapse. Accurate reports of homicides and suicides depend on accurately classifying the intent of the perpetrators of the acts resulting in these deaths. Maltreatment can include both acts of commission (abuse) and omission (neglect), as well as a variety of types of harm or endangerment (physical, sexual, or emotional). The condition of homelessness can be assessed with respect to time (temporarily, episodically or chronically homeless) or location (living on the streets, in temporary housing, or doubled up with relatives). Immigrants and refugees encompass those who are here legally as well as those who are not, and among the former, settlers, sojourners and commuters (permanent residents, temporary visitors, and those who regularly cross the Mexican or Canadian borders to work, respectively) are all included.

Quality of Data Sources

Another important problem in estimating the number (or prevalence) and health status of people who are vulnerable is that the quality and completeness of the data sources for identifying them are limited. These sources may include clinical diagnoses of disease, patient self-reports of illness, vital statistics inventories on births and deaths, and health and social service agency records on clients.

Different sources tend to yield variant estimates of those in need within a particular group, which also make direct comparisons of the magnitude of need across groups difficult. Different universes (or groups) of individuals are used as the basis for different estimates. Further, estimates based on survey

data (such as the prevalence of alcohol or substance abuse or family violence) may also have systematic biases resulting from only selected groups or individuals being included in or responding to the survey, as well as variable (sampling) errors associated with the size and complexity of the sample design.

Changes over Time

Trend data that document increases in certain types of problems (such as child abuse and neglect) are also confounded with the increased visibility and likelihood of reporting these types of events. Often data are not available in a timely fashion or vary in quality and completeness across studies and sources. Cutbacks in funding, as well as changes in definitions of cases over time (which may be warranted to capture the changing dynamics of the problem, such as AIDS), can nonetheless jeopardize the availability of longitudinal data to trace changes in the incidence or prevalence of these problems.

Lack of Subgroup Data

The lack of demographic identifiers or detail (by race and ethnicity, for example) can also limit analyses of differences between groups for whom the risk or magnitude of problems are most likely to vary.

Many people have more than one type of health problem. Low birthweight babies may have congenital defects or other adverse outcomes associated with prematurity that result in long-term physical or mental impairment. Particularly high-risk categories of mothers and infants include those in which the mother or her sex partner(s) used drugs or were HIV-positive. Pregnant women with abusive partners or those who are homeless or fleeing political persecution are particularly at risk of poor outcomes for themselves and their unborn children. Accurate national estimates on the number of these and other groups with a multiplicity of cross-cutting needs are not readily available. Examination of data for discrete subgroups should not, however, obscure the mosaic of physical, psychological, and social needs that characterize the lives of many of the vulnerable.

WHAT PROGRAMS ARE NEEDED?

The health and health care needs of vulnerable populations are best addressed by a long-term, prevention-oriented continuum of programs and services.

The programs and services that might comprise such a continuum include (1) primary prevention-oriented community resource development and public health programs; (2) treatment-oriented care delivered primarily through the medical care and related professional service delivery systems; and (3) long-term care institutional and community-based programs and services. The organization and integration (more often lack of integration) of these programs does not typically acknowledge the emergence and evolution of vulnerability over the life course of individuals, as well as its essential roots in the communities from which people emerge, and to which they return after being treated by the formal professional service delivery systems.

HOW SHOULD POLICIES BE RESHAPED?

Heath care reform is proceeding at a rapid-fire pace at the state and local level, through the widespread adoption of managed care in both the private and public health care sectors. The numbers of privately insured individuals enrolled in these arrangements continue to grow, as does the proliferation of federal waiver requests submitted by states to expand managed care under the Medicaid program.

This market-oriented approach to health care reform focuses on the management of and competition between discrete providers of services. It is manifest in the proliferation and consolidation of provider networks into integrated systems of delivering and financing medical care, that impose varying constraints on providers' fees and consumers' utilization of services.

Applying community-oriented lenses to these developments would seek to illuminate the resultant distribution of and linkages between providers along a continuum of prevention-oriented, treatment-oriented, and long-term care.

A community-oriented health policy to address the health and health care needs of vulnerable populations acknowledges the essential social origins and consequences of poor physical, psychological and/or social functioning, and the array of community-based, nonmedical social and community support services required to ameliorate both the risk and consequences of vulnerability.

It also considers the distribution of programs and services across social and economic strata within the community.

To begin to attend to the dimensions and scope of the problem of vulnerability to poor health in the United States, policymakers must come to envision a sense of community, and the normative compass and context it provides.

Features of such a policy are, for example, manifest in the formation of community-based organizations and consortia to develop programs and services for persons with AIDS, the homeless, and chronically mentally ill; the development of community-oriented primary care (COPC) models of service delivery; school-based clinics; and client- or family-centered outreach and case management services.

A broader set of goals and objectives is required to more fully capture the scope and impact of a community-oriented approach to health policy.

It seeks to surface and address the overt and covert attitudes and practices, reinforced by both local and larger institutions (such as business, the media, governmental entities, and special interests), that constrain the regard, power and opportunities accorded different age, gender, and racial/ethnic **social status** groups.

It simultaneously acknowledges, draws upon, invests in, and generates the essential and important nonmaterial **social capital** resource by inviting, listening to, and maximizing the participation, involvement, and empowerment of individuals and groups within the community in defining priorities and developing resources to address them.

It seeks to enlarge the **human capital** assets and investments (such as jobs, schools, housing, and other resources)that undergird and enrich the immediate and long-term productive potential of those who live, work, and raise and care for their families in those neighborhoods.

It envisions a blueprint and a team of architects -- from the public and private sectors and affected communities -- to undertake the design of a comprehensive, integrated, prevention-oriented continuum or **system** of programs and services accessible to all members of the community.

It embraces a comprehensive definition of health and well-being, and embodies a restive, normative judgment of **outcomes**, motivated by assessments of the extent to which the health of the community as a whole, not just individual patients or clients within it, can be improved.

SUMMARY

In summary, the perspective developed here argues that ultimately the remedies for our individual and collective vulnerability are found in the bonds of caring human communities. The invitation to understand and address the health and health care needs of vulnerable populations may, in fact, take on a renewed significance with the recognition that **"they"** may, at any time, become **"we"**.

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ACKNOWLEDGEMENTS

The author acknowledges the granting of copyright permission by Jossey-Bass Inc., Publishers, for the use of selected excerpts (pp. 1-8 and 238) of: Aday, Lu Ann. At Risk in America: The Health and Health Care Needs of Vulnerable Populations in the United States (San Francisco: Jossey-Bass, 1993).

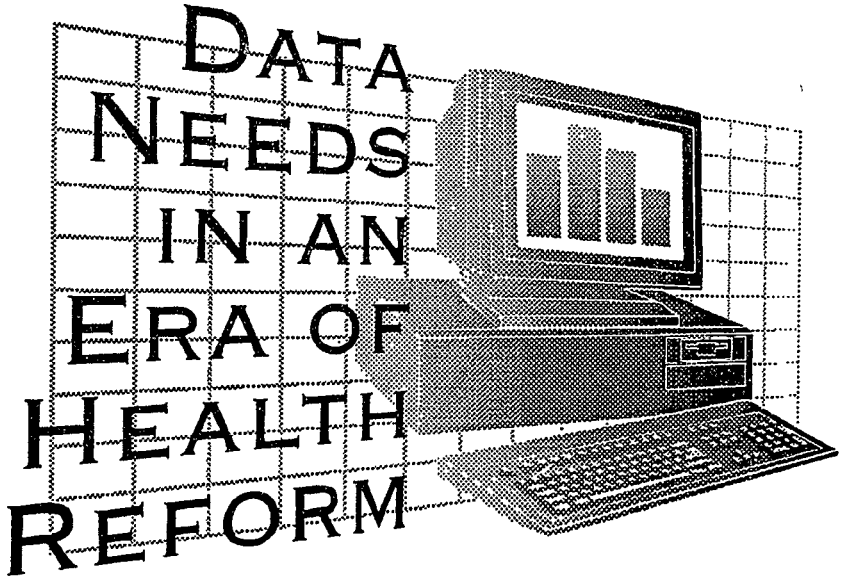
THE POTENTIAL OF HEALTH REFORM FOR VULNERABLE POPULATIONS: A CHALLENGE FOR PUBLIC HEALTH

E. Richard Brown, University of California at Los Angeles

Paper not available for publication

Session I

Mothers and Infants



INFANT SLEEPING POSITION IN NORTH CAROLINA: STATE HEALTH MEASURES FOR EVALUATING THE BACK TO SLEEP CAMPAIGN

Jack K. Leiss
N.C. State Center for Health and Environmental Statistics

Good morning. I'm going to report to you this morning on a survey of infant sleeping position we did in North Carolina. I'm going to present this as a state health department response to a sudden, unexpected data need. I will focus on two aspects of the survey: the study design, which may have introduced bias into our results, and how we attempted to adjust for that; and the administrative and political context, which affected the timing of the survey and its adequacy as a response to an unexpected data need.

Our interest in sleeping position begins with our interest in sudden infant death syndrome (SIDS). We are interested in SIDS because it is the major cause of postneonatal mortality, and it receives considerable attention in the public and political arenas. As a state health department, there was little we could do to prevent SIDS. In trying to understand SIDS in our population, we note that the rates have been declining for years, but the reason for this decline is unknown.

Recently, evidence began to accumulate that placing the infant to sleep on its back or side reduces the risk of SIDS. The evidence was strong, but incomplete. In North Carolina, and I expect in most other states, this was met with uncertainty on the part of the public, and clinicians were reluctant to change the recommendations they were used to giving their patients. In the face of this, state health officials were hesitant to develop a policy on sleeping position and to implement a program to effect that policy.

Then in June of 1994, the Public Health Service and several other agencies began a national campaign (the "Back-to-Sleep" campaign), aimed at parents and providers, to get parents to place their infants to sleep on their backs or sides. State health officials suddenly found themselves confronted with questions they did not have the data to answer:

1. What is the compliance with these recommendations in our state?

2. What is the effect of this on SIDS?

3. How does this differ among our various population groups?

In order to answer these questions, we would have to know current and past prevalence of infant sleeping position, by population group, so that we could assess past and future changes in sleeping position and relate these changes in SIDS. However, the reality of the situation was that we had no baseline data and no control over timing — the national campaign was going ahead whether we were ready or not. Furthermore, we had no resources that could be immediately applied to this problem, and we had little local experience to go on as far as this particular issue goes. In addition, although our researchers perceived the need to collect this data as soon as possible, preferably before the start of the national campaign, our administrators did not share that perception.

We did eventually mount a survey. It's objective was to collect baseline sleeping position data, including "retrospective" baseline data, on the North Carolina infant population aged 2 to 4 months. We reached this population by sampling birth certificates and conducting telephone interviews with the mothers. Questionnaire items came from a survey that had been conducted by the National Institute for Child Health and Human Development (NICHD). We asked about sleeping position for the current and previous infant. Our target population was the June 1994 birth cohort, restricted to blacks and whites and resident in-state births. We traced the phone numbers by linking the birth certificates to the health department file that contained information on local health department clients and WIC and MEDICAID clients. Only the infant's mother was accepted as a respondent.

Perhaps the most creative aspect of our response to this unexpected data need was the way we funded the survey. The Survey Operations Unit did not have a budget that could be used for this purpose. So we called around to various health department programs — WIC, maternal and child health, injury control, immunizations, and adult health — and invited them to participate in the survey by providing questions for the instrument and funds for the budget. We also received funds from the Healthy People 2000 grant that our center has from CDC. In this way, we assembled a minimum budget for the survey. With these funds, temporary help was hired, but other resources were scarce. Only one researcher (J.K.L.) was involved in the project, and little additional office space or computers were available. Our unit did not have interviewers to make the telephone

calls. One thing we did have going for us, however, was wonderful cooperation from several agencies within the department. The BRFSS unit, for example, did the interviews for us, and the print shop turned our questionnaire around overnight, even though there was a two or three week waiting list. It was like that everywhere we turned. Without that cooperation, we could not have done the survey.

In evaluating the survey as a response to an unexpected data need, timing is one of the most important issues. Very early in 1994, we tried to generate interest in a sleeping position survey, but that was moving along slowly. Then around March, we learned of the imminence of the national campaign. At that point, we began recruiting resources in earnest. By June, the first memos had been written. In August, final authorization was received, funding was finalized, temporary help was hired, the questionnaire was finalized, and the sampling frame was received. The sample was selected in September, and we verified (by hand!) that these were not cases of infant death or adoption. Following a pilot study, telephone numbers were traced and interviews conducted in September - November.

Figure 1 shows the development of our sample. There were 7,839 eligible births in the June cohort, but only 5,496 of these were included in the sampling frame we received from Vital Records. The remaining 2,343 births had not yet been reported to Vital Records. We could have begun with a more complete frame by using the May cohort, but that would have given us an infant population older than what we were aiming at, so we decided to go with the incomplete frame. Of the sample that was subsequently selected, about half were not contacted, primarily because correct telephone numbers were not obtained for them. Nearly everyone contacted agreed to an interview.

Figure 1 indicates two potential sources of bias — the incomplete sampling frame and the high rate of noncontact. We adjusted for these using standard methods of poststratification based on data from the birth certificates, which we had on the entire June cohort, not just those interviewed. The incomplete sampling frame was poststratified by hospital of birth and race. The contacted sample was poststratified by race, maternal education, and maternal age. I can provide further details of these adjustments if you wish.

Table 1 shows the prevalence of the recommended sleeping position by race and sex for the current and previous birth. Previous birth here represents about 2 to 4 years ago. At that time, there was little difference in prevalence between blacks and whites — all were at around 35 percent. For the current birth, both groups show increased use of the recommended position, but whites have increased slightly more than blacks.

Table 1. Prevalence (%) of back or side sleeping position

Race	Males	Females
	Current Birth	
Blacks	45.8	48.1
Whites	59.0	53.4
	Previous Birth	
Blacks	36.1	33.8
Whites	38.8	36.7

What can be learned from our experience? Regarding the study design: the most important thing was to be able to act quickly. Using birth certificates as the sampling frame enabled us to do this. The birth certificates were immediately available to us at no cost, and they gave us access to the general population. They also provided a considerable amount of data on the entire target population at zero marginal cost. All of these were distinct advantages to us. On the other hand, because of the time needed between obtaining the sampling frame and conducting the interviews, we had to use an incomplete frame, which may have introduced bias. In addition, since we relied on tracing telephone numbers based on birth certificate information, we had a high rate of noncontact due to untraced numbers. This also may have introduced bias.

In the future, a complete sampling frame could be achieved by sampling and interviewing in two stages, i.e., as we did, and again some weeks later when the rest of the births have been reported. For our purposes, this would have given an infant population that was older than we needed. Alternatively, it may be

possible to conduct a brief supplemental survey of the omitted part of the frame to collect information to use in adjusting for bias. However, my preference would be to concentrate resources at an early stage of the survey to shorten the lead time and thereby be able to start with a more complete frame.

Regarding the high rate of noncontact, it was not feasible for us to conduct a mail survey of those for whom we did not have telephone numbers. However, there were several instances where the number we had was to a relative (the respondent not having a telephone at her residence), we left a message, the respondent called us back, and we obtained an interview that way. This leads me to believe that, in the future, we should mail letters to those for whom we do not have telephone numbers, inviting them to call in for an interview. In this way, we may be able to increase coverage.

When we first began to plan the survey, we were not at all certain that we would be able to pull it off in time and obtain useful, important data. It would have been better if we could have collected the data before the start of the national campaign. Nonetheless, our results give important information that will be used to guide the current SIDS prevention program in North Carolina and to evaluate future changes in SIDS.

There is a lesson here for administrators. That is that it may be necessary, in the interest of the public's health, to embark on a nontraditional data collection effort before it is politically comfortable to do so. Since we can expect such instances to become increasingly common, mechanisms should be established to anticipate unexpected data needs and respond to them as they arise.

Thank you.

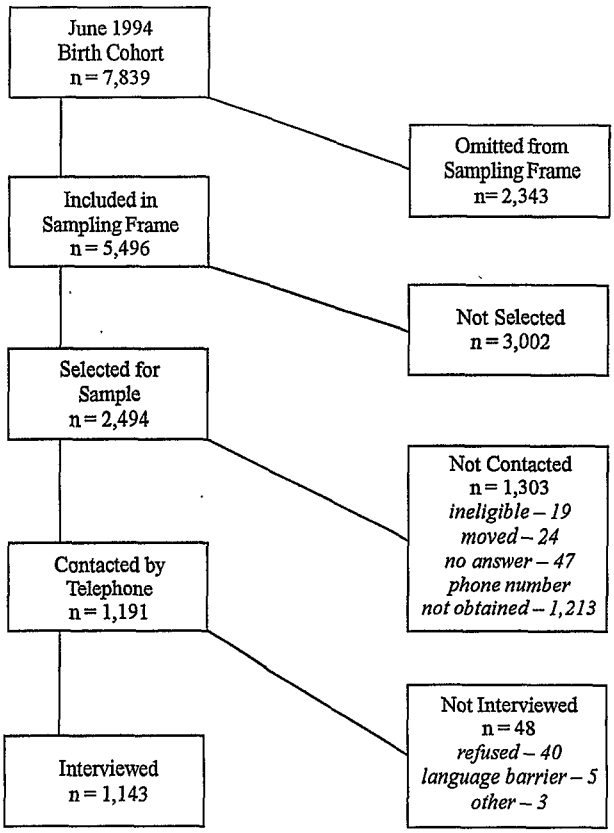


Figure 1. The 1994 North Carolina Current Birth Cohort Survey. Development of the Study Population.

BIRTH PRODUCT LINE QUALITY MANAGEMENT REVIEW

David C. Schutt, Colonel, USAF, MC, Department of Defense
Raymond S. Crawford, III, MD, MBA
Henry Krahauer, CAPT, MD, Ph.D., PHS

BACKROUND

The Military Health Services System (MHSS) has 8.25 million beneficiaries world wide. These beneficiaries are cared for by 50,000 providers in 120 hospitals and over 500 clinics. The MHSS generates a million admissions a year and 50 million outpatient visits a year.

The MHSS is under the same pressure to change as civilian medicine. That is to decrease costs while maintaining quality. Managed care seems to provide some of the tools to accomplish this transition. In addition, the Department of Defense is using capitation to budget for health care. The MHSS is implementing both of these in a managed care program called TRICARE.

Births are the most common reason to be admitted to a military hospital. Therefore, births were chosen as the first "product line". The Birth Product Line analyzes the clinical outcomes, processes of care and resource utilization associated with the care of 9700 mothers and newborns from the first prenatal visit to discharge. This analysis results in the production of a Clinical Practice Profile which elucidates best clinical practice.

GOALS

The goals of the Birth Product Line study were:

- Determine the influence of patient characteristics and processes of care on clinical outcomes
- Determine the influence of patient characteristics and processes of care on resource utilization
- Develop Clinical Practice Profiles by hospital that describe performance in terms of clinical outcomes and resource use
- Identify the processes of care that lead to desired clinical outcomes - Best Clinical Practice
- Disseminate this information to the MHSS
- Enable providers to incorporate Best Clinical Practice patterns in their hospitals

BEST CLINICAL PRACTICE

Best Clinical Practice is the combination of processes of care that produce a optimal clinical outcome with the most cost effective use of resources. This concept can be visualize as follows:

$$\text{BEST CLINICAL PRACTICE} = \frac{\text{OPTIMAL CLINICAL OUTCOME}}{\text{COST EFFECTIVE RESOURCES}}$$

STUDY RATIONALE

Births are the most common reason to be admitted to a military hospital and are the largest generator of beddays. Pregnancy and child birth are the most common reason for a malpractice claim and as more women join the active duty force, women's health care issues become a greater concern.

The Birth Product Line study will enable military hospitals to improve the quality of care for mothers and newborns while reducing clinical risk and costs.

The DoD has now gone to a capitated funding model for health care. This model switches the funding philosophy from a "fee per service" to a "fee per person" approach. In order to live within these new constrained budgets, providers are now asking four questions:

- Which processes of care should we stop doing?
- Which processes of care should we continue doing?
- Which processes of care should we keep doing but improve?
- Which new processes of care should we start doing?

The birth product line study attempts to begin a methodology to answer the clinicians questions.

STUDY DESIGN

One hundred births were randomly sampled at 97 military hospitals. The cases were followed from the first prenatal visit to discharge of mother and baby. The cases reviewed were delivered between October 1992-September 1993.

The analysis of the data was done in five stages:

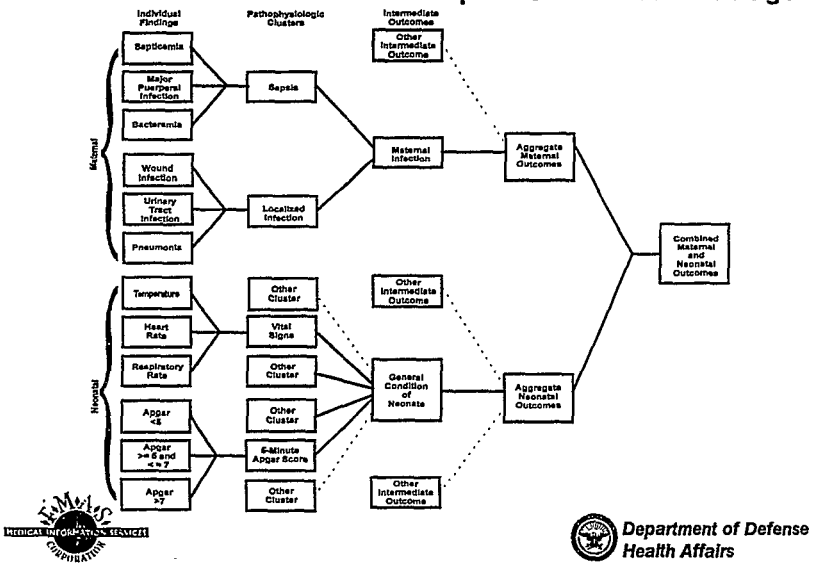
- Establish patient risk adjustment factors
- Determine the processes of care delivered to the patient
- Determine the clinical outcomes and assign a severity score
- Establish a resource use model
- Determine influence of processes of care on clinical outcomes and resource use

One hundred nine risk factors were identified by clinicians which might affect the outcome. They also identified 47 processes of care which were delivered to the patients.

Each clinical outcome was assigned a severity score of 0-12 where 0 is no abnormality or finding and 12 is death (Figure 1). Each clinical outcome is a compost of separate

Figure 1

How Combined Outcomes are Developed from Individual Findings

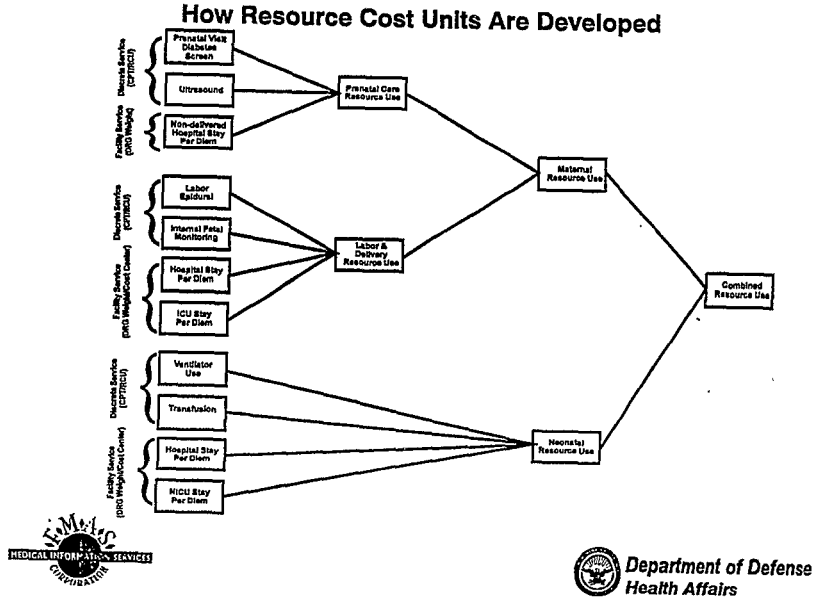


findings such as extent of blood loss or respiratory complications. These findings were assembled into pathophysiologic clusters. The clusters were grouped to form intermediate maternal, e.g., genital tract trauma, infections, and neonatal outcomes, e.g., prematurity, infections, trauma, etc. The intermediate outcomes were combined to form aggregate maternal and aggregate neonatal outcomes and finally these two were combined to form the Combined Maternal and Neonatal Outcome.

Resource Cost Units were developed for maternal utilization, neonatal utilization and a combined utilization (Figure 2). The cost units have two components: (1) physician charges for services and procedures and (2) hospital charges for services provided. Physician charges were calculated using ICD-9-CM codes and CPT-4 codes. Hospital charges were calculated using CHAMPUS DRGs.

Figure 2

How Resource Cost Units Are Developed



FINDINGS

Figure 3, a Clinical Practice Profile (CPP), attempts to solve the best clinical practice relationship, e.g., optimal clinical outcome with the most effective use of resources. The x axis displays the difference in the predicted resource use and actual resource use. The y axis displays the difference in the predicted outcome and the actual outcome. Best clinical practice is based on the practice patterns of hospitals that currently produce optimal clinical outcomes at the most effective use of resources. Figure 3 shows using a CPP the combined maternal and neonatal clinical outcome performance and resource utilization for outlier hospitals. Hospitals are outliers if their clinical outcomes and resource utilization are better or worse than predicted. The five hospitals identified with dots are the five with the best clinical practice.

As an example, look at Hospital E. In Figure 3 Hospital E is in the lower right hand quadrant. Their combined maternal and neonatal outcomes are not a good as predicted and their resource utilization is higher than predicted. How does the rate at which they use certain processes of care compare with the rest of DoD? Table 1 provides the answer. For example, diabetes screening lowers or improves the outcome score by .27 units. It lowers the resource utilization by .04 units. Hospital E performs diabetes screening 79% of the time while the DoD on average performs the screen 82% of the time.

The five best hospitals are in the left upper quadrant of Figure 3. How often do they perform this screen and how does Hospital E compare? Table 1 shows in the far right hand

Figure 3

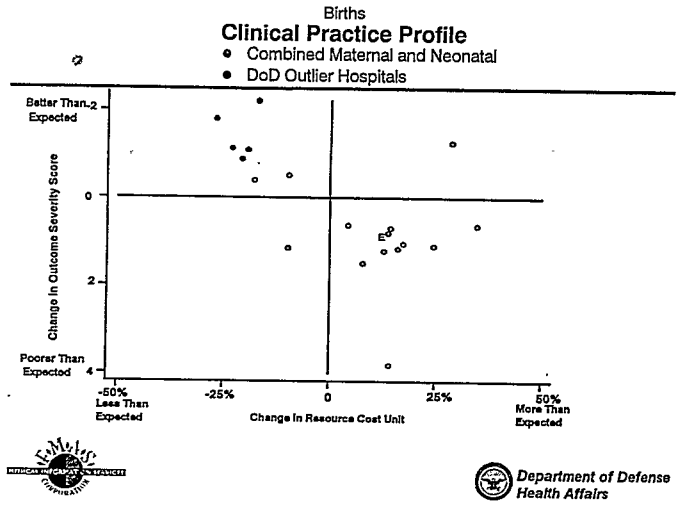


Table 1

Births

Impact of Processes of Care on Combined Outcomes and Resource Utilization

Process of Care*	Change in Outcome Severity Score	P Value	Proportional Change in Resource Cost Unit	P Value	Hospital E How Often Performed	DoD How Often Performed	MTFs with Better Than Expected Performance How Often Performed
Pre-admission Interventions							
External version attempted, antepartum	-0.57	0.06	0.12	0.00	2.02%	1.50%	1 60%
Diabetes screen performed	-0.27	0.01	-0.04	0.00	78.79%	82.30%	87 50%
Total number of prenatal visits (average, per patient)	-0.04	0.00	0.00	0.01	10.0	11.9	11.0
Number of ultrasound tests performed (average, per patient)	0.11	0.00	0.04	0.00	2.6	1.9	1.3
Ultrasound testing performed	0.42	0.02	0.04	0 01	93.94%	91.70%	82.30%
Pre-delivery Interventions							
External fetal monitoring only	-0.30	0.00	-0.04	0 00	46 46%	29 60%	31 40%
Artificial rupture of membranes	-0.26	0 00	-0.05	0.00	44.44%	53.20%	50 40%
Internal uterine pressure catheter monitoring	0.40	0.00	0.04	0 00	33.33%	32.90%	26.00%
Epidural anesthesia for labor	0.61	0.00	0.10	0.00	59.60%	19.10%	11 10%
Fetal scalp pH tested during labor	1.60	0 00	0.10	0.06	10.10%	0.60%	0.00%
Delivery Interventions							
Outlet or low forceps extraction	1.20	0.00	0.10	0 00	22 22%	4.80%	1.70%
Non-elective cesarean section	1.98	0.00	0.41	0.00	16.16%	10.60%	11.60%

*Processes of care with p values <0.05 are considered statistically significant.

column that in the five best hospitals diabetes screening is performed almost 88% of the time.

If Hospital E performed all of the processes of care evaluated in the study at the same rate as the top five hospitals, how much improvement would Hospital E experience? The answer is in Figure 4. The financial impact of this change in practice pattern is displayed in Table 2. If Hospital E performed these processes of care at the same rate as the top five hospitals, Hospital E could save $1.4M while maintaining or improving the technical quality of care. The entire DoD could experience a savings of $38M if all of its hospitals performed the way the top five performed.

Figure 4

Births

Clinical Practice Profile

- Combined Maternal and Neonatal
- Region 1

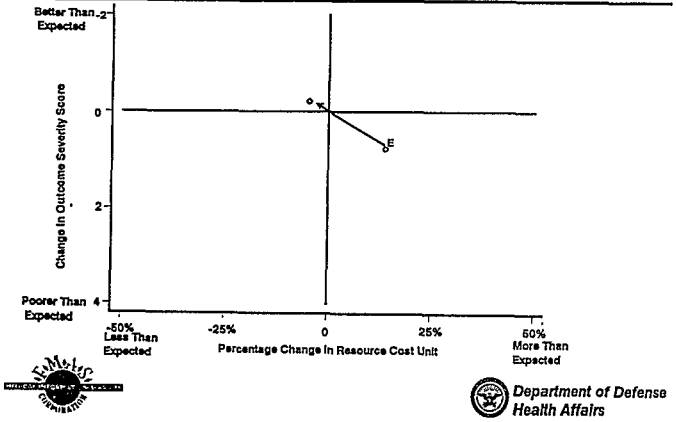


Table 2

Births

Change in Outcome Severity Scores and Relative Cost Units Based on the Practice Pattern of the Five Best MTFs

Organization Unit	Change in Outcome Severity Score	Change in Relative Cost Unit	Total Cases	Savings Per Case ($)	Total Savings (Millions $)
Hospital E	-1.00	-52.75	858	-1,661.63	1.43
DoD	-0.31	-16.90	71,037	532.42	37.82

NEXT STEP

Over the next two years the program will:

- Begin to answer the clinicians' four questions
- Disseminate the findings of this study to the clinicians
- Repeat the study in FY96 to include the civilian hospitals in the DoD network
- Offer support to hospitals in the interpretation of the studies and the implementation of its findings

METHODOLOGY FOR THE EVALUATION OF THE NEW JERSEY HEALTHSTART PROGRAM: HEALTH OUTCOMES OF COMPREHENSIVE MATERNITY AND PEDIATRIC PREVENTIVE HEALTH CARE

Maryanne Florio, New Jersey State Department of Health
Susan Lenox Goldman, and Leah Ziskin

Introduction

In 1988 the New Jersey State Departments of Health (NJDOH) and Human Services (NJDHS) initiated HealthStart, a Statewide enhancement of Medicaid comprehensive maternity and pediatric preventive health care services. The goals of this program were to improve access to quality health care for low income pregnant women and children to the age of two, with a resulting improvement in health outcomes, especially infant mortality, low birth weight, and immunization rates.

Key Features of the HealthStart Program

The key features of the NJ Health-Start program include provision of an enriched comprehensive package of medical maternity and health support services with case coordination; pediatric preventive health care services; increased provider reimbursement; and Medicaid expansion through Jersey Care and presumptive eligibility.

The health support component is the unique aspect of HealthStart maternity services. It consists of assessment, guidance, counseling, and referral for nutrition, social, psychological needs and support, and health education, with an individualized plan of care and case coordination of all services. Specialized services, basic and extensive laboratory testing, and home visits for high risk patients may be provided directly or by referral to agencies with whom collaborative agreements have been made. Case coordination is considered the key component of the health support services component.

The comprehensive packages of maternity services are available at HealthStart-certified hospitals, community-based agencies, and private-practice settings. Published standards of care and guidelines, developed and revised with involvement of community-based agencies, help to ensure the consistent delivery of quality care at all provider sites. Medicaid providers who apply and meet the criteria, become certified by the Department of Health as HealthStart providers. Currently, there are 260 certified medical practices providing HealthStart medical maternity care and 108 certified comprehensive maternity care sites providing the health support services.

HealthStart pediatric services include nine preventive child health visits in two years and age-appropriate immunizations in accordance with the national recommendations. Providers are also required to provide or arrange for outreach, counseling, sick care, and referrals, where appropriate.

HealthStart services are provided to an increasingly larger population of poor women by expanding eligibility, to 100% of the Federal poverty level in 1988, and to 185% in 1991; and through presumptive eligibility which allows a woman to be determined eligible by the provider and receive services while waiting for her Medicaid eligibility to become approved.

Evaluation Methodology

The evaluation of the HealthStart program was mandated as part of the HealthStart legislation, and planned and developed prior to the implementation of the program. The ability to conduct an evaluation was enhanced by this early planning and legislation. The Health-Start evaluation was initiated to assess the effectiveness of the program in terms of both process and the outcome, and addressed five specific research question: how successful has the HealthStart program been in 1) improving access to quality maternity and pediatric health care services for low income pregnant women and children, 2) providing delivery of quality comprehensive services by certified providers, 3) reducing barriers to the delivery of services to this population, including language and cultural barriers, 4) improving health outcomes of participating women and children, and 5) providing a cost-effective package of services?

A six-year evaluation study has been conducted of this program. NJ has used several methodologies to determine the impact of the HealthStart program.

Data Collection Methodology

HealthStart Linked Data System:

The key methodology used in the evaluation of HealthStart is a linkage of five databases: 1,2) NJDOH Vital Statistics birth certificate files matched to the infant death certificate files, 3) NJDOH hospital uniform billing discharge files (UB 82), and 4,5) NJDHS Medicaid claims and eligibility files. This linked data system (HSLDS) consists of individual records for all single, live, in-hospital births to NJ residents. The number of single live NJ births on the HSLDS was 89,500 in 1985, and increased each year, to 113,300 in 1990. Medicaid births represented approximately 15% of these births in 1985, and increased to 20% by 1990. HealthStart accounted for 3% of the Medicaid population in its first year, 1988, and increased to 65% by 1990. At the present time, the HealthStart program serves approximately 90% of the Medicaid population of pregnant women and young children.

The HSLDS also contains a medical

history profile of all mothers from three months prior to conception through three months after delivery, and a comparable medical profile for all children up to the age of 36 months. Also, the files are linked across all years since 1985 so that a woman's entire pregnancy history for all of her pregnancies and medical history is linked.

The linkage of the files for the baseline years of 1985 through 1987, and the first three years of the HealthStart program, 1988 through 1990, has been completed through a collaborative effort with the NJ Department of Treasury, Office of Telecommunication and Information Services at a 93% to 96% match rate across all files, and includes 100% of the birth records in NJ each year. The linkage is nearly completed for 1991 and 1992, and is anticipated to be done for 1993 in the near future. The NJ WIC data system is also being linked to the HealthStart Linked Data System (HSLDS) at the present time.

This unique data linkage enables NJ to make extensive comparisons of health outcomes and costs for women and children who receive HealthStart services with other Medicaid pregnant women and their children, and with all other pregnant women and young children in NJ who did not receive Medicaid funds. Although the HSLDS system has been costly, time and staff intensive, and has experienced delays because of major changes in the birth certificate file, and the Medicaid claims and eligibility system, it has been an invaluable tool in the evaluation of HealthStart and in providing information on maternal and child health issues in NJ.

HealthStart Maternity Services Summary Data:

A second major source of data is an in-depth collection of pregnancy-related information maintained via the HealthStart Maternity Services Summary Data (MSSD) form since the initiation of the program for each woman receiving HealthStart services. It is currently available through 1993 for each woman receiving HealthStart services, and includes demographics, risk factors, services received, pregnancy outcome, and health status of the mother and her newborn. These data were available early in the evaluation and were used initially for preliminary process and evaluation data, and provider quality assurance. At present they are used to produce indicators of effective program implementation, access to and provision of services, and confirmation and extension of the linked data system to more recent years.

Pediatric Preventive Health Care Data:

Third, providers of HealthStart pediatric services submit an individual patient report form for each pediatric preventive health care visit. The data used in the analysis of the HealthStart pediatric program are based on 375,000 visits by 175,00 children (unduplicated) under the age of two years.

HealthStart Provider Tracking System:

The fourth major data source is the Provider Monitoring System, a system of information on each provider, including certification, technical assistance visits, staffing patterns, and recertification. It has been developed to assist in the monitoring, quality assurance, technical assistance, and certification of the HealthStart provider agencies.

Limitations of Data

As with all data there are limitations to these data sets: 1) portions of the data are self-reported and therefore, some of the sensitive data, for example drug use, may be underreported; 2) there is a chance of error in completing forms, in data entry, or in data processing (extensive systems of edit checks have been developed to control for data errors); 3) some of the data are incomplete; (The number of MSSD forms submitted is not equal to the number served. This appears to be random in all but one agency who submit their forms electronically, and experienced a delay because the electronic system was not implemented until 1991. Also, not all of the records were linked in the LDS. The percentage of non-linked records is higher in the Medicaid population, but this appears to be a random non-linkage of HealthStart and non-HealthStart Medicaid women.) 4) there is a potential selection bias for HealthStart women, i.e., the more motivated or healthier women may have chosen to participate in the program, which could potentially result in healthier outcomes due to differences other than those due to the impact of the HealthStart program. (There are three ways in which this bias has been tested. First, HealthStart women were found to be nearly identical to other Medicaid women in the observable characteristics: age (33% teens, 3% over 34), race/ethnicity (60% black, 30% Hispanic), marital status (80% not married), and education (50% had less than high school)[1]. Secondly, the results of a survey of all women who received HealthStart services showed that availability was the predominant determinant of participation[2]. Lastly, a study conducted by an independent population and economic researcher showed that women who participated in HealthStart were actually more at risk for adverse outcomes than other Medicaid women[4].

Confirmation of Data

Checks of key sensitive and self-reported data have been made with data from other studies. For example, checks were made of self-reported data on drug use by HealthStart women by comparing their data with data from a statewide drug study on pregnant women, which showed that HealthStart self-reported data were approximately five percentage points lower than the drug study data.

Outcome Data and Findings of the HealthStart Evaluation

The results of the evaluation show that the HealthStart program has been successful in providing access to enhanced quality health care services and improving health outcomes for low income pregnant women and children. The most significant results of the provision of the HealthStart model are listed below as answers to the five principle research questions.

Increased Access to Health Care:

- In 1988 the HealthStart agencies provided access to the enhanced package of services to 8,000 women. The HealthStart program is now providing prenatal care services to more that 90% of the population of pregnant Medicaid-eligible women, approximately 35,000 women at 108 comprehensive maternity provider sites, of whom approximately one-half deliver in a given year;
- In 1988 10,500 pregnant women received HealthStart services through the presumptive eligibility process; by 1993, this increased to 23,700 women;
- Entry into prenatal care in the first trimester increased from 33% in 1988 to 40% by 1992[2];
- In 1988 HealthStart pediatric preventive health care was provided to 6,600 children; it is now provided to approximately 38,000 children a year by more than 300 providers[3];

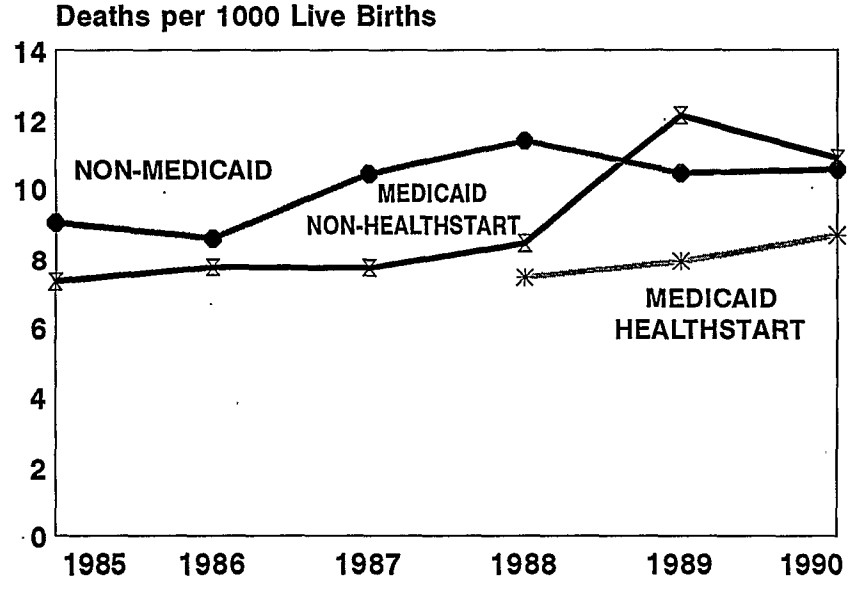
Provision of Enhanced Quality Prenatal Care Services:

- HealthStart agencies provide the entire package of enhanced prenatal care services to 95% to 100% of the women who go to a HealthStart agency[2];
- HealthStart women and children receiving WIC increased from 65% in 1988 to 80% by 1992[2];

Improved Health Outcomes for Newborn of HealthStart Mothers:

- Fewer black (non-Hispanic) babies of mothers who received HealthStart services died in their first 27 days of life (neonatal mortality) than babies of other black (non-Hispanic) Medicaid women, and surprisingly, than black (non-Hispanic) babies of non-Medicaid women (7.5, 7.9, and 8.7 deaths per thousand live births to HealthStart women compared to 8.5, 12.1 and 10.9 deaths per thousand live births to Medicaid non-HealthStart women, and 11.5, 10.4, and 10.5 deaths per 1000 live births to non-Medicaid women in 1988, 1989, and 1990 respectively, $p < .0001$[1], Figure 1);
- Fewer black (non-Hispanic) very low birth weight babies (less than 1500 grams) were born to women who received HealthStart services than to other black (non-Hispanic) Medicaid, and again surprisingly, non-Medicaid pregnant women (1.34%, 1.45%, and 1.58% of HealthStart newborn had very

Figure 1: Neonatal Mortality (0 to 27 Days) Comparison of Black Non-Hispanic Newborn

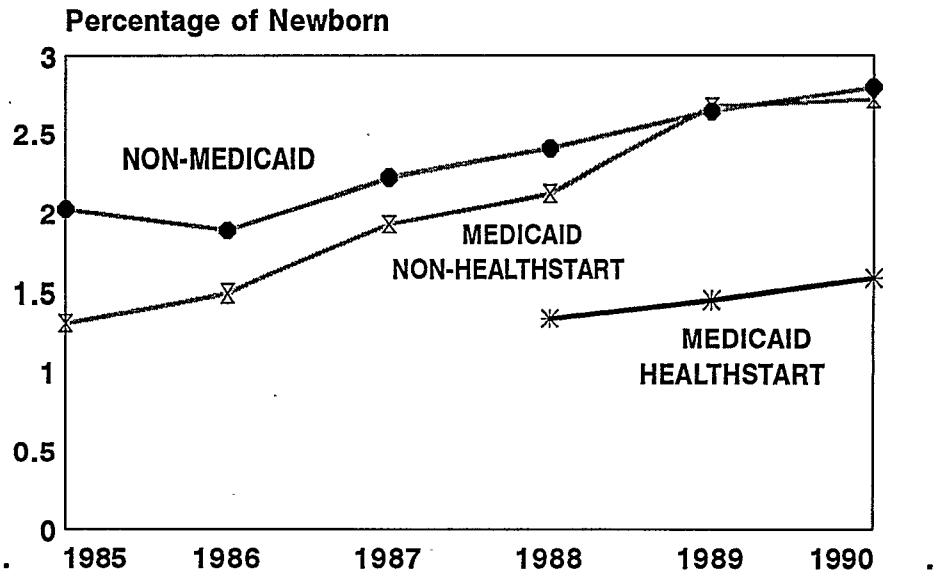


Source: NJ HealthStart Linked Data System

low birth weight compared to 2.12%, 2.67%, and 2.72% of Medicaid non-HealthStart newborn, and 2.40%, 2.64%, and 2.80% for non-Medicaid newborn in 1988, 1989, and 1990 respectively, $p < .001$[1], Figure 2);

- Newborn of women who received HealthStart prenatal care services had significantly lower infant mortality, especially neonatal mortality than newborn infants of other Medicaid women (6.2, 5.6, and 6.3 neonatal deaths per 1000 live births for HealthStart newborn compared to 7.3, 8.3, and 9.1 deaths for Medicaid non-HealthStart women in 1988, 1989, and 1990 respectively, $p < .0001$[1]);
- The percentage of moderately low birth weight newborn of women who received HealthStart prenatal care services decreased from 8.9% in 1988 to 6.7% in 1992; also, a significantly lower percentage of moderately low birth weight babies were born to HealthStart women than to other Medicaid women (7.9%, 7.9%, and 7.2% of HealthStart women had moderately low birth weight newborn compared to 8.3%, 10.0%, and 9.4% of other Medicaid women in 1988, 1989, and 1990 respectively, $p < .005$)[1];
- The percentage of very low birth weight newborn of HealthStart women decreased from 2.0% in 1988 to 1.1% in 1992; also, a significantly lower percentage of very low birth weight babies were born to HealthStart women than to other Medicaid women (1.0%, 1.2%, and 1.2% of HealthStart women had very low birth weight newborn compared to 1.6%, 1.9%, and 1.9% of other Medicaid women in 1988, 1989, and 1990 respectively, $p < .005$[1]);
- The percentage of well newborn infants of HealthStart women increased from 71% in 1988 to 84% by 1992[2];
- There was a comparable decrease in the percentage of HealthStart newborn infants with medical problems, the most common of which were respiratory distress, sepsis, apnea, cardiac distress, and drug withdrawal, from 15% in 1988 to 7% in 1992[2];
- There was a decrease in the use of the neonatal intermediate or special care nursery from 15% in 1988 to 9% in 1992[2];
- There was a decrease in the percentage of HealthStart infants hospitalized since birth or rehospitalized from .28% in 1988 to .06% in 1992[2];
- There was a high age-appropriate immunization rate of 79% for the three most important childhood immunizations for children completing HealthStart pediatric services (DPT, polio, and MMR) when compared with the Statewide average immunization rate of 40% to 50%[3];

Figure 2: Very Low Birth Weight (Less than 1500 grams) Comparison of Black Non-Hispanic Newborn



Source: NJ HealthStart Linked Data System

Improved Health Outcomes for the HealthStart Mother:

- Substance abuse decreased during pregnancy: drugs from 5% to 1%, alcohol from 6% to 2%, and smoking from 24% to 12% by the time of delivery[2];
- The percentage of uncomplicated labor and deliveries increased from 59% in 1988 to 70% in 1992[2];

Cost Savings

- Reported charges for births of HealthStart newborn infants ($1,739) were significantly lower than those of other Medicaid newborn infants ($2,068)[1];
- The cost savings estimate for the decrease in the percentage of newborn infants admitted to the NICU in 1990 based on the reported charge of $8,300 per infant was $4.1 million in 1990, nearly the entire cost to NJ for the HealthStart services provided in that year[1,2].

Other Studies Using the HealthStart Data

Confirmation of NJ HealthStart Evaluation:

In addition to the evaluation of the HealthStart program conducted by NJDOH and NJDHS, a collaborative evaluation of the HealthStart program was conducted with an independent evaluator, an economic and population researcher. Using the HealthStart Linked Data System, and ordinary and two-stage least squares multivariate analysis of variance as the primary statistical procedure, this study confirmed the results of the NJ evaluation findings that HealthStart has had an impact on maternal and infant health outcomes and costs[4]. This study also confirmed that self-selection bias was not a limiting factor of the findings. HealthStart women were found to be nearly identical to other Medicaid women in age, education, race, and marital status; and to be even more at risk of adverse outcomes than other Medicaid pregnant women.

Factors Related to Low Birthweight:

A multiple logistic regression was performed using SAS LOGIST to determine the relationship between low birth weight (less than 2500 grams) and three sets of variables in the MSSD data: the HealthStart woman's demographic and behavioral characteristics, and her service utilization[5]. The Odds Ratios based on the multiple logistic regression, adjusted for all other variables in the model, showed that women younger than 20, older than 34; unmarried; or black; and those who smoked, drank, or used drugs; had a significantly higher risk of a low birth weight baby. Women who received future family planning, childbirth education, or WIC (three of the tenets of services provided by the HealthStart program,) or had a male baby, had a significantly lower risk of a low birth weight baby (Table 1).

Table 1: Logistic Regression and Adjusted Odds Ratios for HealthStart Maternal Characteristics and Low Birth Weight Newborns

CHARAC.	ADJ. ODDS RATIO	CHARAC.	ADJ. ODDS RATIO
AGE		**RISKS**	
<20	1.3*	Smoker	1.6*
20-34	1	Not Smoker	1.0
35+	1.7*	Drinker	1.4*
MARITAL STAT.		Not Drinker	1.0
		Drug User	1.8*
Married	1.0	Not User	1.0
Not Marr.	1.2*	**SERVICE**	
RACE/ETH		Family Plan.	.8*
White	1.0	No Fam.Plan.	1.0
Black	1.8*	Childbir.Ed.	.9*
Hispanic	1.1	No Child.Ed.	1.0
Other	1.6*	WIC	.9*
SEX OF BABY		No WIC	1.0
Male	.8*		
Female	1.0		

* p<=.05, 95% C.I. does not include 1.0

Transfer of HealthStart Model of Prenatal Care and Application of HealthStart Evaluation Methodology to Managed Care

The HealthStart model of prenatal care has been extended in many hospital-based agencies to all women who come for prenatal care. In 1992 and 1993 the model was expanded to include the non-Medicaid population up to 300% of the Federal poverty through a joint collaboration of the NJDOH, NJDHS and U.S. Healthcare.

NJ is now in the process of adapting the program and the evaluation methodology as we implement a Medicaid managed care system for the AFDC population. A comparable methodology to that used in the evaluation of the current HealthStart program is being used to evaluate the HealthStart program under the managed care system.

Notes:

1. HealthStart Linked Data System (which excluded multiple births and out-of-NJ hospital births).
2. HealthStart MSSD data (which includes all births; the percentages are somewhat different, therefore, in this data set than in the Linked Data System).
3. HealthStart Pediatric Preventive Health Care Visit Form.
4. Nancy Reichman and Maryanne Florio. "The Effect of Enriched Prenatal Care Services on Medicaid Birth Outcomes in New Jersey" Princeton University Office of Population Research Working Paper No. 95-2: Princeton, New Jersey. January 1995.
5. Lucille Wallington. "A Study of the Determinants of Low Birthweight Among HealthStart Program Participants in New Jersey" Unpublished paper to fulfill the requirements for the Columbia University Enhanced Analytical Skills Program in cooperation with New Jersey Department of Health. May 1993.

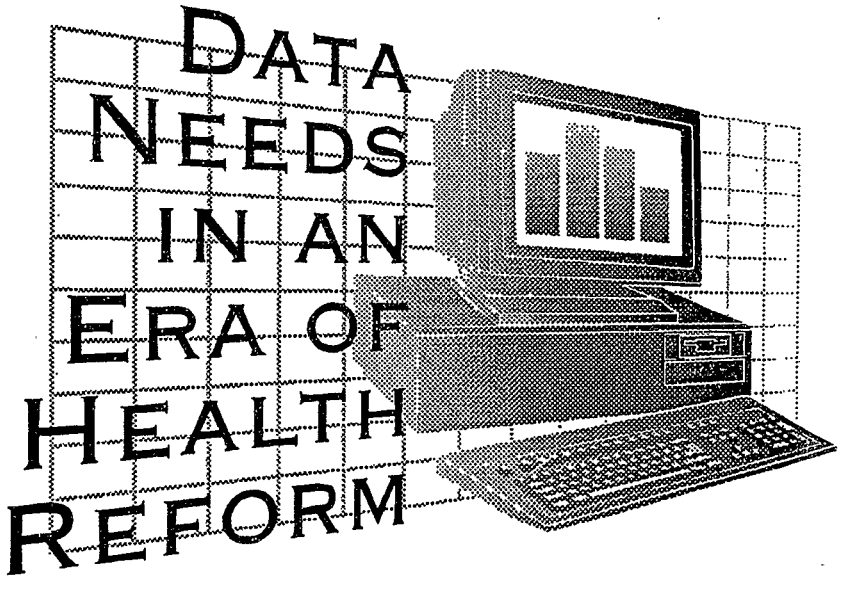
MOTHERS AND INFANTS
Discussant

Woodie Kessel, Maternal and Child Health Bureau

Comments not available for publication.

Session J

Cognitive impairment of the elderly



MEASUREMENT OF COGNITION IN AHEAD: METHODOLOGICAL AND SUBSTANTIVE INVESTIGATIONS

A. Regula Herzog, University of Michigan
Robert B. Wallace, University of Iowa

The Asset and Health Dynamics Among the Oldest Old (AHEAD) study is a biennial survey of a nationally representative sample of more than 8,000 community-residing persons 70 years old and older in 1993/94. The survey focuses on health transitions in late life and their economic and family consequences. Because cognitive changes are an important component of such transitions, an effort was made to properly measure cognition. A broadly differentiating measure was sought to investigate change in cognitively well functioning as well as in already impaired persons. Persons between 70 and 80 were interviewed primarily on the telephone, persons over 80 face-to-face.

The dimensions of memory for new information and working memory -- or the ability to keep information in store while processing it -- were considered important for the measurement of cognition in the AHEAD because they are known to decline throughout a good part of the adult life span. The dimension of established knowledge was considered important because it is thought to decline less substantially and at a later point in the life span than memory.

These dimensions of cognition were represented by the following measures. Memory for new information was measured by an immediate and a delayed free recall test of 10 nouns. Working memory was measured by Serial 7s (i.e., 5 consecutive subtractions of 7 from 100). Established knowledge was measured by vocabulary items and by questions on orientation in time, space, and history. These measures were adapted from the Telephone Interview for Cognitive Status (TICS) developed by Brandt and colleagues (1988).

In psychometric terms, the different measures interrelate moderately (average r = .24), indicating a common underlying construct of cognition. The different dimensions were probed with factor analytic techniques. An exploratory factor analysis suggests a memory factor and a factor including all other measures. A confirmatory factor analysis that models a working memory factor in addition to the memory and "knowledge" factors fits the data well, potentially supporting a separate working memory component.

These cognitive measures differ considerably in difficulty level (Table 1). The delayed recall measure is most difficult, the knowledge measures are easiest, the Serial 7s and immediate recall measures are of intermediate difficulty. Furthermore, the measures do provide the desired differentiation at higher as well as lower levels of cognitive functioning. For example, about one quarter of respondents who did poorly on the delayed recall measure could still answer correctly all knowledge questions. Or, about one quarter of respondents who correctly answered all knowledge questions, could recall only 2 or fewer words in the delayed condition.

Missing data are not always negligible; about 3, 3, and 12 percent of the respondents refused to answer to the immediate memory, delayed memory, and Serial 7s tasks, respectively. Fewer refused the knowledge questions. Several observations suggest that respondents who refused did not know the answer: (1) refusals are higher on difficult than easy measures; (2) refusals increase with age; (3) those who refused Serial 7s did no better on the knowledge measures then those who did not refuse but obtained a low score and they described their cognitive functioning as no better; (4) those who refused looked similar on several health measures to those who did not refuse but obtained low scores. These findings suggest that incorrect answers can be imputed for refusals, a conclusion also reached by other investigators.

A total cognitive score was formed by summing the single measures after imputing incorrect scores for refused answers. This measure yields an approximately normal distribution, which is quite different from the skewed distributions obtained with typical geriatric mental status scales in community populations.

An important methodological issue facing the AHEAD design was whether the mode of interviewing would affect the performance on the cognitive measures. It seemed possible that a cognitive test would be more difficult to administer and to respond to over the telephone than face-to-face. Because in the AHEAD design mode was confounded with age and thus presumably with capacity, adjustment for these differences was necessary. OLS regression analyses of cognitive functioning on mode with and without controls for initial differences showed an uncontrolled difference of three points on the aggregate measure to shrink to a difference of less than one half point with controls. This finding suggests that most of the mode difference was compositional and not due to mode of administration per se.

Another important methodological issue facing AHEAD is whether being present at a household member's interview improves performance on the cognitive measures for the second household member to be interviewed. A difference of more than one point on the aggregate measure was found, even after a number of differences between household members had been controlled, suggesting that there is a learning effect associated with listening in on the test administration to a different person (Rodgers, unpublished tabulations).

A final issue is whether the cognitive measures in AHEAD show construct validity by replicating established findings and by behaving in theoretically predicted ways. An OLS regression analysis shows the following replicated findings. Adults who are old, have little formal education and are in relatively bad physical health perform relatively badly on the aggregate cognitive measure. Less well established but theoretically sensible findings include positive effects of hearing and vision, of high income and assets, of moderate drinking, and of a lack of difficulties with activities of daily living on cognitive performance.

In summary, the AHEAD experience demonstrates that cognitive performance measures can be administered by lay interviewers in large scale survey efforts. Despite limited time, a broadly differentiating measure of promising validity was obtained. Aspects of surveys such as missing data and mixed modes did not represent unsurmountable problems. Whereas other aspects such as the effect of educational attainment and of interviewing respondents in the same household will need further attention, the cognitive measures developed for AHEAD have positioned it well for investigating the effect of cognitive functioning and changes therein on economic and family resource use.

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Funding for the AHEAD Study was by the National Institute on Aging grant U01 AG09740.

TABLE 1

Difficulty Levels of Cognitive Tests

Immediate recall: Mean # of 10 nouns	4.4
Delayed recall: Mean # of 10 nouns	2.9
Serial 7s: Mean # of 5 subtractions	3.1
Knowledge items: Mean # of 4 dates	3.6
% counting backwards correctly	90%
% naming scissors correctly	98%
% naming cactus correctly	83%
% naming president correctly	89%
% naming vice-president correctly	72%

COMMUNITY SCREENING FOR DEMENTIA: THE MINI MENTAL STATE EXAM (MMSE) AND MODIFIED MINI-MENTAL STATE EXAM (3MS) COMPARED

I. McDowell[1], E. Kristjansson[1], G.B. Hill[1], R. Hébert[2]

1. University of Ottawa 2. Hôpital de Sherbrooke

The Mini-Mental State Examination (MMSE) was developed as a bedside tool to evaluate the cognitive status of elderly people in clinical settings (1); it is also used as a survey instrument to screen for cognitive impairment and dementia (2,3). It is brief and easy to administer, and has shown good reliability (2). Validity as a screening test is generally acceptable (3), although certain limitations have been identified, for example with psychiatric patients (4), and in identifying focal brain dysfunction (5) or mild dementia (3). On a practical level, the MMSE lacks an administration manual, so that scoring and interpretation seem to vary between users (6).

In 1987 Evelyn Teng proposed the Modified Mini-Mental State Exam (MMMS, or 3MS) to respond to these issues (7). She added four items to cover a broader range of cognitive functions and difficulty levels. The complete 3MS covers orientation to time and place, registration, recall, simple language, and construction. Teng also increased the scoring range from 30 to 100 points to provide finer discrimination, and she produced a detailed manual to standardize administration. Preliminary validity and reliability results for the 3MS were good: test-retest reliability ranging from 0.91 to 0.93, and a sensitivity of 91% for dementia, at a specificity of 97% (7). As most items in the MMSE and 3MS overlap, an MMSE score can be derived from the 3MS with the addition of a few extra questions.

The 3MS requires slightly longer to administer and to score than the MMSE and so is worthwhile only if it offers significantly superior validity. We address two questions:

1. Is the validity of the 3MS superior to that of the MMSE in a community sample?
2. If so, is the improvement due to the broader scope of the 3MS, or to its more detailed scoring system, or to both?

The comparison in a community sample is relevant because screening tests often do not perform as well in general population samples as they do in more highly selected clinical samples (8). The severity of dementia is generally higher in clinical referral samples than in unselected population samples, which inflates the estimate of sensitivity compared to that obtained in a population sample (9). Validation in a community study, however, must address methodological problems such as verification bias. This occurs where people are selected to receive the gold standard clinical examination on the basis of their scores on the screening test. Typically it is not feasible to clinically examine everyone, and so all the subjects who screen positive, but only a sub-set of the majority who screen negative, are referred for diagnostic work-up. The resulting bias inflates estimates of sensitivity and diminishes specificity; methods have been described for its correction (10-13). The bias also affects the area under the receiver operating characteristic curve (AUC), an indicator of validity (13).

Methods

The data are taken from the Canadian Study of Health and Aging (CSHA), a multi-centre study of the epidemiology of dementia, health and disability among Canadians aged 65 and over (14). Eighteen study centres were involved; in the community, an age-stratified random sample (N = 9,008) was drawn; the institutional sample (N = 1,250) is not considered in the present report.

In the community sample, the 3MS was administered as a cognitive screening test in a home interview, in English or French. Interviewers received a five-day training session on administering and scoring the screening instrument. The French

version of the 3MS had been tested previously, giving intraclass correlations of 0.94 for test-retest reliability and 0.95 for inter-rater reliability. Internal consistency was also high (alpha = 0.89, split-half = 0.93) (15). Based on a pilot study (16), a cutting point of 77/78 was chosen as optimal, paying especial attention to maintaining high sensitivity.

Of the 9,008 community subjects, 8,949 completed the screening interview and 2,398 were referred for clinical assessment. These included 1,673 who screened positive on the 3MS and 725 who screened negative. Of the 2,398, 39 (1.6%) were found not eligible, 105 (4.5%) were not accessible, and 559 (26.4%) refused to attend the clinical examination. This resulted in 1600 clinical evaluations: 494 on people who screened negative and 1106 on those who screened positive.

A clinical examination verified the presence of cognitive impairment, and provided a differential diagnosis of dementia. Diagnostic criteria were based on the DSM-III(R) (17) and on the ICD-10 (18). The clinical examination involved a medical and family history; a mental status assessment, physical and neurological examination by a physician; and 13 neuropsychological tests. Consensus diagnoses, involving physician and neuropsychologist, were made blind to the 3MS scores. They classified the person as cognitively normal (N = 747), cognitively impaired but not demented (CIND, N = 488), or demented (N = 365). Dementia was classified into probable Alzheimer's disease, possible Alzheimer's disease (with or without a vascular component) multi-infarct dementia and unclassifiable dementia. The CIND diagnosis represents an attempt to classify people with recognizable cognitive decline that did not currently meet the criteria for dementia. This group was sub-divided into age-associated memory impairment, impairments due to psychiatric illnesses, vascular problems and apparent very early stages of dementia. In this paper we do not distinguish between these sub-categories.

Validity analyses used the receiver operating curve (ROC) approach, comparing the screening tests graphically and statistically across a range of possible cutting points (19). The area under the ROC curve (AUC) indicates the amount of information provided by the test: a test performing no better than chance would have an AUC of 0.5 and a perfect test would have an AUC of 1.0 (19). All validity analyses were corrected for verification bias. A program was written in Basic for this, following the method outlined by Gray and Begg (10). This uses the distribution of 3MS scores for the screening sample and the diagnostic status of those clinically examined at each 3MS score as the basis for calculating corrected sensitivity and specificity for each score.

The AUC indicates the overall performance of a screening test across all possible cutting points; in practice, however, one uses a single cutting point. The choice of a suitable cutting point should consider the relative importance of false positive and false negative errors. This can be formalized by assigning a weight to represent the relative importance of avoiding each type of error, and an optimal cut-point can then be chosen for each test. This is often done implicitly; one way to make the process explicit is through a decision theory approach in which the chosen cut-point is that which equates the ratio of the posterior probabilities of false positive and false negative errors with the reciprocal of the ratio of their costs, or dysutilities. In comparing two screening tests, the one that produces the lower expected loss is to be preferred. We made this comparison for the 3MS and MMSE, varying the cost ratios from 1:10 to 10:1, and identifying the cut-point that produced the smallest expected loss for each test at each cost ratio.

Results

The 3MS was acceptable to most subjects. Fifty-nine out of 9,008 were unable to complete the 3MS test; upon clinical examination, 63% of these were demented and 22% were cognitively impaired.

A comparison of the English- and French-language samples (N = 1166 and 434, respectively) indicated that they were comparable in age and gender, but that the French language sample had

lower educational levels (an average of 6.8, compared to 9.2 years; F = 114.7, df = 1, p = .0001; Table 1).

Table 1. Validation Sample Description

mean	English (n=1166)	French (n=434)	Total (n=1600)
Age	80.3	79.1	80.0
Education	9.2	6.8	8.6
3MS score	73.5	71.3	72.8
MMSE score	23.1	23.0	23.1

There were also significant differences in diagnosis between the English and French samples (chi-square = 6.2, df = 2, p = .04; Table 2). Accordingly we analyze the performance of the screening tests separately in the two groups.

Table 2. Validation Sample: Diagnosis

	English (n=1166)	French (n=434)	Total (n=1600)
diagnosis			
Normal	45%	51%	47%
CIND	31%	30%	30%
Demented	24%	19%	23%

Internal consistency. The alpha internal consistency coefficient for the 3MS (English sample) was 0.87; split-half reliability was 0.82. The consistency of the MMSE was lower: coefficient alpha was 0.78 and split-half reliability was 0.76. The contrast, however, is largely due to the greater number of items on the 3MS; application of the Spearman-Brown formula to correct for the different lengths of the two tests (20) shows that the MMSE would have a coefficient alpha of 0.86 if it had the same number of items as the 3MS. Both scales had lower internal consistency in the French-language sample: α = 0.82 for the 3MS and α = 0.74 for the MMSE; the split-half figures were 0.79 and 0.73, respectively.

Validity of MMSE and 3MS

Dementia versus non-dementia. At the cut-off of 77/78 chosen for our study and correcting for verification bias, the 3MS had 87% sensitivity for detecting dementia and a specificity of 89% in the English-language sample. The ROC curves are shown in Figure 1 and suggest that the performance of the 3MS was superior to the MMSE at almost all cutting points. The area under the curve for the 3MS was 0.94, and that for the MMSE was 0.89 (Z = 5.38, p < .01).

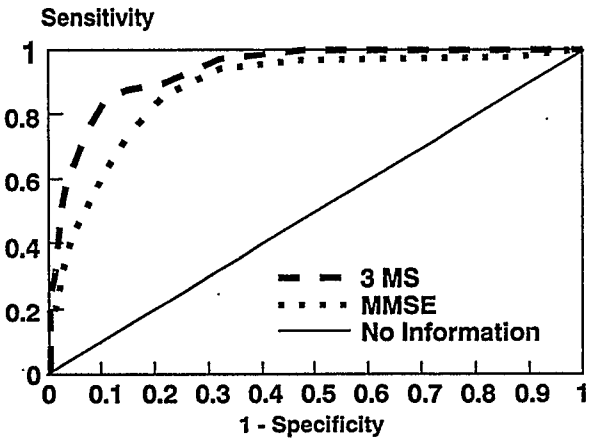

Figure 1. ROC Curves for 3MS and MMSE for Dementia

To illustrate whether the difference between the two ROC curves in identifying dementia holds clinical implications, Figure 2 presents the specificity of the two tests at comparable sensitivity levels (English-language sample). At sensitivity levels up to 0.93, the MMSE would falsely classify as demented about 7% more people than would the 3MS. At higher sensitivities, the advantage of the 3MS increases.

This contrast is further illustrated by comparing the minimum expected losses produced by the tests for particular cutting points reflecting various weightings of false positives versus false negatives (Table 3). The 3MS is always slightly superior to the MMSE; the contrast becomes stronger as sensitivity is weighted more heavily. For example, when false negatives are weighted as 10 times more important then false

Table 3: Comparison of Minimum Expected Loss of MMSE and 3MS Screening Tests in identifying Dementia, at various ratios of the cost of False Negatives to that of False Positives.

	MMSE			3MS		
Loss Ratio (False Neg/ False Pos)	Optimal Cut-Point	Sens., Spec.	Minimum Expected Loss	Optimal Cut-Point	Sens., Spec.	Min. Expec Loss
1:10	8	3, 99.9	.088	31	6, 99.9	.08
1:3	13	8, 99.5	.083	42	13, 99.9	.063
1:2	15	16, 99.5	.082	50	22, 99.6	.06
1:1	16	20, 99	.076	61	41, 99	.053
2:1	20	31, 98	.14	67	56, 97	.087
3:1	22	44, 95	.186	69	61, 96	.116
6:1	24	63, 89	.27	74	76, 92	.169
10:1	25	86, 77	.33	77	86, 87	.218

positives, the optimal cut-point for the 3MS is 77 and the expected loss for the 3MS was 0.22 compared to 0.33 for the MMSE at its optimum cut-point of 25.

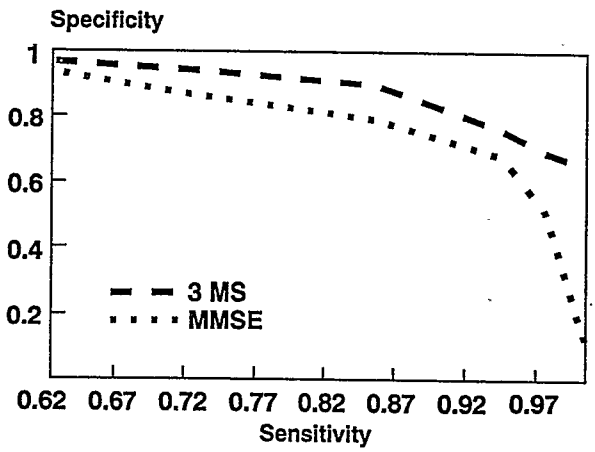

Figure 2. Comparison of Specificity at Various Sensitivity Levels

Dementia + Cognitive Impairment versus Normal. If the task is to distinguish all levels of cognitive impairment (i.e., CIND plus dementia) from cognitive normality, neither test performed well. The performance of the 3MS was very slightly superior to that of the MMSE; the 3MS had an AUC of 0.80, compared to 0.78 for the MMSE ($p < 0.05$) (see Figure 3). The minimum expected losses calculations again showed the 3MS to be slightly superior.

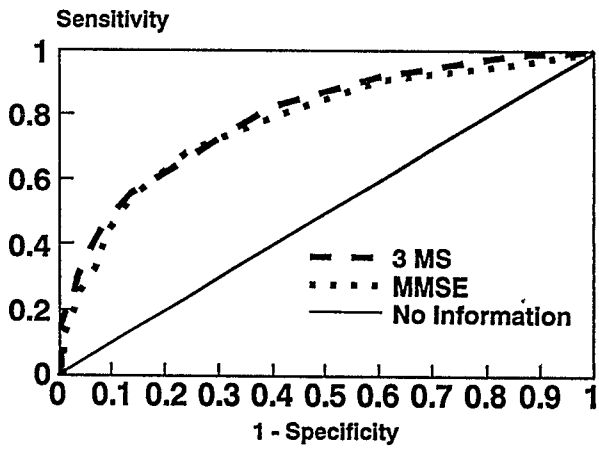

Figure 3. ROC Curves for 3MS and MMSE in Screening for Cognitive Impairment and Dementia

Extended Length versus Scoring. Was the superiority of the 3MS due to its greater length, or to the altered scoring system? If the relative advantage of the 3MS were due to its wider range of scoring alone, then there should be no difference in validity results for the two tests if the 3MS questions were re-scored to conform to the approach used in the MMSE. Retaining the added items, but re-scoring the 3MS using the approach of the MMSE, yielded an AUC of 0.90, only marginally higher than the 0.89 of the MMSE, and lower than the 0.94 for the 3MS as correctly scored.

If the advantage of the 3MS were attributable to the four extra questions, there should be no difference in validity of the MMSE and the 3MS if scores for the 3MS were re-calculated omitting the four new items but using the 3MS scoring method for the remaining items. The AUC for dementia for the 3MS without the four questions was 0.91, lower than for the complete 3MS (0.94), but higher than the 0.89 for the MMSE. These results suggest that the superiority of the 3MS is due to both changes, with very slightly more of the effect being due to the changes to the scoring procedure.

Discussion

The study suggests that the extra time and cost of using the 3MS translates into more accurate screening results than those achieved using the MMSE. The contrast is illustrated when the results are mapped back onto the full community sample of 8,949 people. For example, at a loss ratio of 2:1, the 3MS would miss an estimated 228 cases of dementia and would falsely classify an estimated 392 normal people as demented. At the same loss ratio, the MMSE would have missed an estimated 491 cases of dementia at the cost of 263 false positives. Changing the false negative to false positive loss ratio to 10:1, the 3MS would miss an estimated 85 cases of dementia in the sample and an estimated 1098 normal people would be referred unnecessarily for clinical examinations. The MMSE would miss an estimated 106 cases of dementia and would have entailed 1864 unnecessary clinical examinations.

The increased accuracy of the 3MS appears due both to the additional questions and expanded scoring. The expanded scoring increases test variance which results in improved validity, other things being equal (20). It also allows for finer discrimination. It is reasonable that the additional items should enhance the validity of the test: they assess recall, which is one of the most significant impairments in cognitive impairment and dementia, long-term memory which is a criterion for dementia in the DSM-III-R, and verbal fluency and abstraction, which are commonly impaired in dementia.

The present sample is large and representative of the type of elderly person likely to consult with primary care physicians. Our "gold standard" diagnosis of dementia followed established criteria and used a thorough examination that included neuropsychological testing. Inter-rater agreement on diagnosis was high, comparing well with findings of other studies. Generalizability was enhanced by comparing the tests in two language groups. The correction for verification bias provides valid figures for sensitivity, specificity and loss functions.

Overall, Teng's 3MS does improve on the MMSE, although there is still room for improvement, especially in the identification of early dementias.

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COGNITIVE IMPAIRMENT AND THE QUALITY OF LIFE OF ELDERLY URBAN COMMUNITY RESIDENTS

Howard R. Kelman, Ph.D.
Albert Einstein College of Medicine
Montefiore Medical Center

Cynthia Thomas, Ph.D.
Gary J. Kennedy, M.D.
Jiming Chen, Ph.D.

Introduction

Deficits in cognitive functioning are prevalent among the elderly. Recent studies of noninstitutionalized populations indicate that 20%, or more, of the elderly show signs of cognitive impairment. Among populations under treatment in mental health clinics, cognitive impairment has been found to be a risk factor for shortened survival and early institutionalization as well as for dementia.

There have been few studies which have investigated the effects of cognitive impairment on the daily lives and activities of elderly men and women residing in the community. Although the impact on caregivers of relatives with cognitive impairment has been studied. Perhaps because the effects of cognitive impairment on the quality of life of clinically diagnosed demented individuals seemed so obvious, further investigation among non-demented impaired individuals may have appeared to be unnecessary.

Within recent years, interest in "Quality of Life" (QL) determination and measurement has grown as a way to assess intervention efforts, and/or change in population health status over time especially with regard to individuals with chronic conditions. Consensus on QL definitions and measurement, however, continues to elude interested investigators. Conceptual (and measurement) schemes range from determination of a limited set of health status variables embodied under the rubic of Health Related Quality of Life to conceptual schemes incompassing 15 dimensions and over 1,000 empirical measures. Clearly, when individuals are sick or chronically ill or impaired, all aspects of life may be affected beyond those traditionally defined as "Health Status" or physical functioning. In this presentation data on the quality of life of community residing elderly persons are related to varying levels of cognitive functioning. The domains and measures of QL are shown below. (See Figure 1)

Figure 1

A. Health

-Medical Conditions
-Sleep Difficulties
-Subjective Health
-Symptoms of Depression
-Behavioral Problems
-Mood (positive affect)

B. Functioning

-Social Support
-Problems with Daily Activities
-Nursing Home Residence

C. Personal Relationships

-Number of Friends
-Contact with Children
-Contact with Others
-Intimacy

D. Activities outside the home

-Gets out of the house
-Religious Attendance
-Organizational Participation
-Working
-Exercise

Sample

Data for this analysis are taken from baseline personal interviews with 1855 community residents at least 65 years of age who were participants in a

longitudinal study of aging and health (Norwood-Montefiore Aging Study [NMAS]). The sample was randomly selected from a list of Medicare beneficiaries living in a neighborhood in the Bronx in New York City. Two thirds of the sample were women, more than half were 75 years of age or older, 41% were married, and 44% lived alone. The mean annual income in 1984 was $12,039. Two thirds had private health insurance in addition to Medicare, and nearly 15% received Medicaid. The small proportions of non-Whites and Hispanics reflect the pattern of housing segregation in the study area.

Baseline interviews were conducted between July 1984 and March 1985 and were the first in a series of semi-annual contacts over 3 1/2 years. The response rate to the baseline interview was 73%. Ninety-five percent or more of baseline respondents were reinterviewed in each successive interview wave.

Measures

The Mini-Mental State Exam (MMSE), an instrument widely used to screen for cognitive impairment, was administered to all study participants at baseline. Developed by Folstein et al., the MMSE assesses signs of dysfunction in orientation, registration, attention, calculation, recall, and language.

MMSE scores range from 0 to 30. Persons with scores of less than 18 are defined as severely impaired, those with scores of 18 to 23 as mildly impaired, and those with scores of 24 and above as unimpaired. Although the MMSE is an easily administered and reliable tool to identify signs of cognitive impairment, scores do not provide clinical diagnoses. Cognitive impairment may result from a variety of mental conditions including dementia, depression, brain injury, and mental retardation.

The QL measures were derived from data embedded in the baseline interview. The measures consist of responses by participants to single items or questions, (eg: number of reported medical conditions, frequency of getting out of the house), or scales we developed from responses to several questions, (eg: number of friends, contact with children and organizational participation), or scales composed of several items, eliciting responses to related questions (eg: subjective health, positive affect, intimacy and social support). Items in each of these scales was given equal weight in arriving at the scale score.

In addition to these QL and Cognitive Impairment variables, other variables included were age (in 5 year intervals), income (in $1,000 units), gender (male, female), education (<than or >9+ years), marital status (currently married or not), living arrangements (alone, with others), race (white, other than white), vision defect (yes, no), hearing defect (yes, no).

Analyses

Two main statistical analytic procedures were performed. First, chi square analyses of differences between the three cognitive impairment subgroups (severe, mild/moderate and unimpaired) in the distribution of responses to each of the measures in the four QL domains. The results of these calculations are shown in univariate Table 1. In our earlier work we noted that sociodemographic and related differences between these impairment groups modified the direction of apparent differences in mortality rates between impaired groups[5]. Accordingly we developed multivariate models to assess the association between the QL measures and levels of impairment while examing the effects of those variables that differed significantly between the three impairment groups. Ordinary and ordinal multiple logistic regression analyses were employed for this purpose.

Results

The results of the Chi Square analyses, shown in Table 1, reveal significant differences between either two or

among all three of the impairment subgroups in 15 of the 17 QL measures. There were no significant differences between the three groups in the number of reported medical conditions and behavioral problems.

The overall pattern of differences reveal that among 6 QL measures differences were evident among the 3 subgroups of impaired persons while for 8 other measures, it was the severely impaired group which differed significantly from both the mild and the unimpaired groups. The mildly and unimpaired groups were not significantly different from each other. There were only two QL measures in which the severely impaired group differed from the unimpaired group but not from the mildly impaired ("organizational participation" and "working").

There were some differences in the pattern of impairment group differences among the other QL domains. In the QL domain "functioning", the three QL measures revealed significant differences among the 3 impairment groups. In the QL domain, "Personal relationships," three of the four measures indicated differences between the severely impaired group and the other 2 groups. Differences between the mildly impaired and unimpaired groups were not significant. The patterns of differences in the "Health" and "Activities outside the Home" QL domains were mixed. The two QL measures that did not reveal significant differences among the three groups were measures located with the "Health domain".

The overall pattern of significant QL differences among the three impairment groups, evident from these results, suggests that with some few exceptions, it is the severely impaired who bear the burden of a constricted Quality of Life, most markedly in the domains of functioning and personal relationships. It is also evident that in the domains of "health" and "activities outside of the home" , and in the domain of "personal relationship" as well, that the quality of life of mildly impaired and unimpaired persons are not markedly different from each other though they each differ from the severely impaired group.

To what extent are these univariate results due to or dependent upon the effects of those variables upon which the three impairment groups differed? A mulitvariable analytic approach in which potential confounders are controlled is required to assess the independent effect of the QL measures. We applied multiple logistic regression procedures for the purpose.

The results of these analyses, performed for each of the QL domain measures, are summarized in Tables 2 and 3. In these two tables the adjusted odds ratios and the 95% confidence intervals of the significant cognitive impairment category, as well as the additional statistically significant variables that emerged are presented. Cognitive Impairment was significant in 13 out of the 18 QL measures analyzed. In each of these analyses differing clusters of variables other than the cognitive impairment category also emerged as significant.

These results paralleled the univariate findings with a few differences. Controlling for the effects of the potential confounders implicated cognitive impairment in two measures in the health domain, behavioral problems and number of reported medical conditions. For the measure, "sleep difficulty" variables other than impairment emerged as significant. In the domain, personal relationships, variables other than cognitive impairment were significant for the measures of "contact with children" and "contact with others".

The effect of these and other modifications assessing the differences among the three impairment subgroups, though of interest and of some importance with respect to the specific QL measures involved, does not abrogate the earlier overall

results of the univariate analyses. These multivariate results, in fact, reinforce and also refine certain of the earlier results, namely that it is the severely cognitively impaired group whose quality of life is most negatively impacted. This is more clearly evident in the health and functioning domains than in the domains of personal relationships and activities outside of the home. In the latter two domains, while the results are somewhat more mixed the QL of the mildly impaired does not appear to be significantly different in these measures than the QL of the unimpaired. Differences between the mildly and unimpaired groups which surfaced in the univariate analysis did not remain significant in the multivariate analyses.

Conclusion

The results of this exercise in studying QL differences among elderly community residents, some with and others without signs of evident cognitive impairment, indicate a greater restrictiveness among those with severe impairment particularly in measures of health and functioning. This perhaps is to be expected. This finding is not as clearly evident in those domains involving personal relationships and in activities involving interactions with organizations and groups. This finding perhaps is not expected. Also not expected was the finding that the QL of mildly impaired persons is not markedly, or at least, significantly different from the QL of unimpaired persons. Appearances of differences between these two groups are due more to sociodemographic and other differences rather than levels of cognitive functioning.

Note should be taken also that though severe cognitive impairment apparently imposes significant restrictions in QL, its effects vary across the QL measures. The importance of impairment in relation to QL varies with the character of the specific QL measure. This finding may suggest avenues of intervention that can ameliorate the QL impact of severe cognitive impairment in specific areas though perhaps not uniformly.

Finally, it should be noted that this study was based on specific measures of QL. The data were taken from interviews with participants in a longitudinal study of aging and health. The study was not specifically designed to be a study of quality of life. In fact, the data antedated more recent interest in QL and its measurement. We do believe, however, that we have generated a reasonable set of QL measures that approximate the QL of the population studied. We achieved modest proportions of explained variances in these analyses, not only because of the specific selection of variables and their metrics, but also because of the sparse literature in this area of study, a problem we share with more recent QL investigators. We believe, however, that we have made a significant, although still modest beginning, and we await further investigation into those issues surrounding the QL of cognitively impaired older people.

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Table 1

Levels of Cognitive Impairment Compared Across Quality of Life Domains and Measures

	Cognitive Impairment Levels		
Quality of Life Domain	Severe vs Mild	Severe vs Not Impaired	Mild vs Not Impaired
Health			
No. Reported Med. Cond.	NS	NS	NS
Subjective Health	*	*	*
Sleep Difficulties	*	*	NS
Behavior Problems	NS	NS	NS
Positive Affect/Mood	*	*	NS
Depression	*	*	NS
Functioning			
Social Support	*	*	*
Problems of Daily Living	*	*	*
Nursing Home Resident	*	*	*
Personal Relationships			
Number of Friends	*	*	*
Contact with Children	*	*	NS
Contact with Others	*	*	NS
Intimacy	*	*	NS
Activities outside of the home			
Gets Out of the Home	*	*	*
Religious Attendance	*	*	NS
Organizational Participation	NS	*	NS
Walking	NS	*	NS
Exercise	*	*	NS

* Chi Square is significant at $p \leq .05$; NS=Not Significant

Table 2

Results of Logistic Regression Analyses Health and Functioning Domains

	Mini Mental State Exam		
Quality of Life Domain	Odds Ratio	95% Confidence Inteval	Other Significant Variables
A. Health			
Number Reported Medical Condition	Not Impaired (1.37)	1.22-1.54	Men, education, vision and hearing defect
Subjective Health	Mild or Not Impaired (1.75)	1.41-2.17	Higher income no vision or hearing defect
Sleep Difficulties	NS	———	Men, white, no vision or hearing defect
Behavior Problems	Severe (2.13)	1.53-2.96	Vision and hearing defect
Positive Affect/Mood	Mild or Not Impaired (2.36)	1.00-2.94	Lives with men others, no hearing defect, younger age?
Depression	Severe (2.39)	1.81-3.17	Lives alone, white, hearing defect
B. Functioning			
Social Support	Severe (1.66)	1.33-2.07	Older, lower income, women not married, vision and hearing defect
Problems with Daily Activies	Severe (2.78)	2.20-3.53	Older, lower income, women not married, vision and hearing defect
Nursing Home Resident	Mild (1.81) and Severe (4.19)	1.36-2.39 2.83-6.21	Older age

Table 3

Results of Logistic Regression Analyses
Personal Relationships and Activities Outcome
of Nursing Home Domains

	Mini Mental State Exam		
Quality of Life Domain C. Personal Relationships	Odds Ratio	95% Confidence Interval	Other Significant Variables
Number of Friends	Mild or Not Impaired (2.21)	1.79-2.74	Younger age, higher income
Contact with Children	NS	———	Women, married, lives alone
Contact with Others	NS	———	Younger age, women, education, married, lives with others
Intimacy	Mild or Not Impaired (1.85)	1.43-2.40	Higher income, women, not married
D. Activities Outside of Home			
Gets Out of Home	Mild or Not Impaired (2.80)	2.22-3.55	Lives alone, married women higher income, younger age, no hearing defect
Religious Attendance	Mild or Not Impaired (1.79)	1.41-2.27	Older age, men, education, no hearing defect
Organizational Participation	NS (p=.067)	———	Older, higher income, education, married, lives alone, non-white, hearing defect
Working	NS	———	Younger age, higher income
Exercise	Mild or Not Impaired (2.94)	2.15-4.02	Younger age, higher income, men, no hearing defect

USE OF THE 1989 NATIONAL LONG-TERM CARE SURVEY FOR EXAMINING COGNITIVE IMPAIRMENT ELIGIBILITY CRITERIA

Mary E. Jackson, The MEDSTAT Group
Pamela Doty

Analyses of the 1989 National Long-Term Care Survey (NLTCS) and its companion Informal Caregiver Survey (ICS) were used to examine the comparability of the cognitive impairment eligibility criteria to the 3+ ADL criteria in the Clinton Administration's long-term care health reform proposal from the Health Security Act. Also addressed by these analyses is the extent to which functional indicators, i.e. ADLs, by themselves, are sufficient for identifying both the physically disabled and severely cognitively impaired population. The NLTCS was used because it provides a nationally representative sample of Medicare beneficiaries age 65+ in 1989 that allows for the generation of national estimates on this population.

The Criteria. The Health Security Act (HSA) specified that a person would be eligible for long-term care benefits outlined in the plan if s/he was disabled in 3 or more ADLs out of five (bathing, dressing, toileting, transferring, eating) or experienced a comparable level of severe cognitive impairment. The bill stated that eligibility based on severe cognitive impairment was to be indicated by a standard mental status protocol(s) indicating severe cognitive impairment, PLUS one of the following: 1 or more ADLs out of the core five (bathing, dressing, toileting, transferring, eating); a serious behavior problem(s) that creates the need for supervision to prevent harm to the individual or others; or an IADL indicating some cognitive impairment.

Operationalizing the Criteria. First, we attempted to operationalize these eligibility criteria using the data items available in the 1989 NLTCS and ICS. The five ADLs specified in the Health Security Act are available in the data set; disability in each ADL was defined as chronic, i.e., having lasted three months or longer and requiring either hands-on or stand-by assistance for performance.

Cognitive impairment eligibility criteria were operationalized using the variant of the Short Portable Mental Status Questionnaire (SPMSQ) available in the 1989 NLTCS. This battery contains 10 items, 9 of which are identical to the SPMSQ. The one item that differs from the SPMSQ is a slightly less difficult item than appears in the original version of the instrument; as such we accept a score of 4 or more errors (rather than 5), to indicate moderate/severe impairment and a score of 6 or more to indicate severe impairment.

We were also able to operationalize the additional criteria that the HSA stipulates must be met for evidence of cognitive impairment. As previously mentioned, ADL items are readily available in the data set (for operationalizing the additional criteria of 1+ ADLs in the CI criteria). The behavior problem items available in the NLTCS are: wandering, frequent temper tantrums, and compulsive stealing. Although these items may not be those one would choose, they were the only proxies available in the dataset, and thus were used to operationalize the behavior problem criteria. And finally, the cognitive IADLs were operationalized with the medication management, money management, and telephoning items.

Comparison Standards. In order to assess whether the cognitive impairment eligibility criteria is comparable to the 3+ ADL criteria a standard of comparison must be used that in some way indicates the level of disability or impairment, other than the eligibility criteria. The NLTCS provides two sources of standards. First, is the number of hours of care per week an individual receives from all sources – from informal sources (family and friends) who are unpaid and from persons who are paid to provide care. The second measure chosen to be used as a standard is an item in ICS which asks the caregiver how many hours the disabled person can safely be left alone.

Results. Table 1 shows that persons meeting the eligibility criteria of 3 or more ADLs receive 70 hours of care per week, on average. However, this estimate includes persons with 4 and 5 ADL disabilities; because such individuals have more needs and therefore receive more hours of care, the average number of hours is somewhat inflated. In order to compare to the CI criteria a fairer approach is to use the number of hours associated with persons having 3 ADLs, which is 51.1 hours per week.

Table 1 also shows that regardless of how CI is operationalized, more loosely or more stringently, the number of hours that those with cognitive impairment receive is always less than the number of hours those with 3 or more ADL disabilities receive. The measure that comes the closest to being comparable is the one that combines behavioral evidence for the need for care/oversight with 6 or more errors on the SPMSQ. This CI measure is the most stringent as it requires evidence of more severity on the mental status protocol.

It should also be noted that the SPMSQ as a stand-alone criteria yields the poorest comparison. But when the protocol is combined with some manifestation for the need for care, comparability is enhanced.

Similar results are obtained when the comparison standard is the number of hours an individual can safely be left alone. Those with 3 ADL disabilities can be left alone for 6.1 hours, on average whereas those with 6+ MSQ errors and some evidence of the need for care can be left alone for 6.7 hours, on average.

Table 1
Total Hours/Week of Care and Hours Alone by Various Disability Criteria

Disability Criteria	Mean Hours of Care	Mean Hours Alone
3+ ADL	70.0	4.1
1 ADL	23.2	12.0
2 ADL	33.7	7.7
3 ADL	51.1	6.1
4 ADL	63.1	4.7
5 ADL	88.4	1.9
4+ SPMSQ Errors	35.2	9.0
6+ SPMSQ Errors	41.7	7.3
4+ SPMSQ Errors AND One of the following: •1+ ADL •Behavior Problem(s) •Cognitive IADL(s)	45.4	8.4
6+ SPMSQ Errors AND One of the following: •1+ ADL •Behavior Problem(s) •Cognitive IADL(s)	50.1	6.7

Table 2 displays the population estimates associated with the 3+ ADL disability criteria and operationalized HSA cognitive impairment criteria in conjunction with the 3+ ADL criteria. The estimates are for the 1989 aged 65 and older population. They indicate that close to one million elders (or 3.2% of the 65+ population) would be eligible for benefits if the sole criteria were 3+ ADL disabilities. When the cognitive impairment criteria are added, an additional 1.3 to 2.0 percent of the population would be eligible, depending upon the exact definition of cognitive impairment.

Table 2
Number and Percent of Aged 65+ Meeting Various Eligibility Criteria

Criteria	Population Estimate	% of 65+ Population
3+ ADL	999,263	≈ 3.2
3+ ADL OR 4+ SPMSQ Errors AND One of the following: •1+ ADL •Behavior Problem(s) •Cognitive IADL(s)	1,638,262	≈ 5.2
3+ ADL OR 6+ SPMSQ Errors AND One of the following: •1+ ADL •Behavior Problem(s) •Cognitive IADL(s)	1,409,233	≈ 4.5

There are obviously some individuals who will meet both the 3+ ADL and CI eligibility criteria. Of those with 3 or more ADL disabilities, between one-third (33.1%) and two-fifths (41.7%) are also cognitively impaired, depending upon how CI is operationalized. And of those who meet CI criteria, approximately 2/5 are also disabled in 3 or more ADLs.

In order to examine whether ADLs might suffice as a stand-alone criteria for identifying both the physically disabled and cognitively impaired, two multiple regression analyses were conducted, one with the dependent variable being total hours of care, and the other hours the person could safely be left alone. The number of ADLs and the combined CI measures were entered as independent variables along with several control variables that are known/suspected to affect how much care a person receives.

The control variables included the care recipient's age, sex and race; the primary caregiver's age, sex and relationship to the care recipient, i.e., spouse or not.

Table 3 presents the regression coefficients associated with the two key independent variables, i.e., ADLs and cognitive impairment. (Coefficients for the control variables are not shown). These coefficients can be interpreted as the number of hours of care (or hours the care recipient can be left alone) associated with each measure. Results indicate that for each additional ADL disability there is an increase of 11.6 hours of care. Cognitive impairment, on the other hand, is associated with a decrease of 3.2 hours.

Table 3.
Predictors of Total Hours of Help and Hours Person Can Be Left Alone

Independent Variables	Hours of Care	Hours Alone
# ADL/5	11.6*	-3.1*
Cognitive Impairment	-3.2	-4.1*
Interaction	3.5	0.8

* $p \leq .05$

An interaction term was also included in the model. It reflects the number of hours a person who is both cognitively impaired and ADL disabled receives. The results indicate those who are cognitively impaired received 3.5 additional hours of care for each additional ADL disability.

Note that the ADL coefficient is the only one that is statistically significant. Cognitive impairment, once ADLs are taken into account, does not add significantly to the hours of care, and neither does the interaction term. ADLs are clearly the strongest predictors of the need for care.

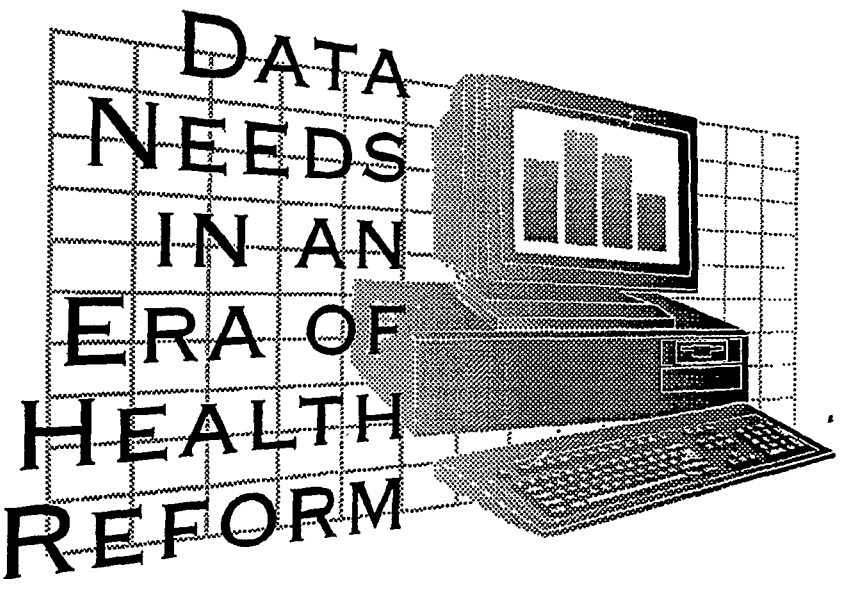
However, the results are somewhat different when the outcome is the hours alone variable. Interestingly, each additional ADL is associated with a person being able to be left alone for 3.1 fewer hours, but cognitive impairment is associated with 4.1 fewer hours. And coefficients for both the ADL and cognitive impairment variables are statistically significant, suggesting that ADL criteria alone is not sufficient for predicting level of care need.

Discussion. The results of these analyses indicate that it may be possible to develop reasonable cognitive impairment criteria comparable to the 3+ ADL criteria, particularly if the cognitive impairment criteria are based upon indicators that reflect true need for care and/or oversight as manifested by functional and/or behavioral factors. Nevertheless, the results also suggest that ADL criteria alone are not sufficient for identifying the severely cognitively impaired, even when disability in an ADL is defined to include stand-by assistance and supervision (in addition to hands-on assistance). However, other function-based measures (e.g., some combination of ADLs and IADLs) may prove effective in identifying this population.

Finally, one must remember that these analyses were based on survey data, and that several of the items used to operationalize the eligibility criteria are proxies for indicators that would be employed in determining program eligibility. Moreover, even if there were a one-to-one correspondence between the survey items and eligibility criteria items, one would still have to offer the caveat that even the most valid criteria can identify an unintended population – in this instance the less than severely cognitively impaired – if not reliably administered, or administered as intended.

Session K

Methodological Issues I



ANALYTICAL METHODS FOR DISEASE PATTERNS AND SOCIOGEOGRAPHY: ECOLOGICAL APPROACHES

Deborah Wallace, Ph.D., Consumers Union

Introduction

Public health examines populations and their health status, thus qualifying more as an ecological discipline than a purely medical science. Adaptation of ecological analytical approaches can yield valuable results in sociogeographic public health research.

Tuberculosis: A Case History of Methodology Transfer from Ecology

How to analyze geographic differences in population health patterns? Figure 1 displays the 1990 tuberculosis incidences of the 30 health districts of New York City. Note two bands of especially high incidence: Southwest Bronx-Harlem and Lower Eastside-Brooklyn corner near Manhattan.

John Sbarbaro (1991) stated that blacks are genetically susceptible to TB. This statement lets public health officials off the hook for high TB rates in segregated areas, despite the fact that the high rates were the basis of Sbarbaro's statement. Figure 2, the major racial components of the 59 NYC community districts (CD's) in 1990 (NYC Planning Dept, 1994) indicates that racial composition cannot explain the 1990 pattern.

Historically, the Tuberculosis Leagues explored the influence of household crowding on TB occurrence (Wichen, 1936). The Index of Extreme Housing Overcrowding of the Census Bureau (percent of dwelling units with 1.51 persons per room or more) of the health districts fits incidence pattern imperfectly but better than race (figure 3): R^2 of nearly 50%. Drucker et al (1994) found housing overcrowding was an important factor in household TB transmission.

Income level, not surprisingly, coincides with the TB pattern (figure 4, 1990 median incomes of the CD's, from New York Planning Dept., 1994) better than race.

Rent imperfectly indicates income. In ecology, we use indices regularly. The reciprocal of average rent indicates functional average poverty. We use this index because we have the average rent data for the 30 health districts but not the poverty levels or median incomes. Indices may be necessary in the use of easily available administrative data sets. The R^2 of this poverty index regressed against 1990 TB incidence is over 40%, close to that of housing overcrowding. But regression of the index of extreme housing overcrowding against the index of poverty yields an R^2 of only 19%, a hint that the two factors are semi-independent.

Although loss of control over TB began in 1975-1976, continuous epidemic process began in 1979. In fact, 1978 was the year of lowest historic citywide incidence. After 1978, TB spread through the City except for the wealthiest neighborhoods (Figure 5 and Table 1). Table 1 shows that only the wealthiest health district escaped the epidemic. The corresponding community district with a median income of $53K also has a high income diversity, with over 15% of the households earning over $150K per year. Diversity measurement was performed on the CD's with the Shannon-Weaver Index of Diversity (Magurran, 1988). In ecology, we developed methods of measuring diversity decades ago.

For a detailed review of events leading to creation of essentially citywide susceptibility to TB, see Bulletin of the NYAM, 66, Sept/Oct. 1990 (Wallace and Wallace, 1990). The poor neighborhoods of color were targeted , beginning in 1969, by successive mayors implementing a policy of "planned shrinkage" which took away housing preservation services such as fire control. Fire and building abandonment flared into literal epidemics, parasites on the housing stock. The Census Bureau counted the dwelling unit loss between 1970 and 1980 in the hundreds of thousands (fig.6: each blackened area is many census tracts each of which lost 500 or more dwelling units). Mass migration resulted, a disruption on the scale of low level war or famine. Citywide TB followed the trends of housing over-crowding (fig.7) during the game of "musical homes", and after 1980, homelessness became rampant (Wallace, 1989 and 1990).

Area population density influences community transmission because of its determination of active case density and density of susceptibles. Table 2 shows the TB cases per square mile of selected health districts in 1978 and 1990. Eighty percent of the 1990 incidence pattern can be explained in a stepwise regression with independent variables of 1978 case density (initial condition) and the 1990 index of poverty (1/average rent). At this scale, two types of transmission obviously occur: household and community.

The 1970's saw the most rapid city-to-suburb migration ever, with 1.3 million whites leaving NYC for the suburbs. Suburbanites kept the jobs in the City, and number of jobs in the City grew through 1990. In 1980, 1,744,433 people worked in Manhattan; by 1990, the number had risen to 2,039,651 (Census Bureau, Journey-to-Work data). In 1980, the density of workers per square mile in Manhattan was 61424; in 1990, it was 71819. Manhattan was and is the heart of the foraging range of 24 counties, about 20 million people. Figure 8 displays the commuting field of Manhattan: percent of a county's workforce which works in Manhattan vs the miles between Manhattan and the center of the county. Even as far as 60 miles away (Fairfield County, CT), over 5% of the workers had jobs in Manhattan in 1990, slightly more than in 1980.

Commuting indicates city-suburb contact. Indeed, the regional structure of TB incidence 1985-1992 reflects the proportion of workers commuting into Manhattan and the poverty rates of the counties (fig. 9). For details of the

composite index of commuting and poverty, see Wallace and Wallace (1995). The TB incidence of the City, determined by the planned shrinkage public policy, in turn determines the suburban counties' TB incidences, modulated by local poverty level.

Processes beginning at the scale of the neighborhood reached down into the households and up into the whole City and the entire metro region. A recent court decision (Rev. Monsignor John J. Powis et al vs Rudolph Giuliani et ano, Index #100990/95, Supreme Court, State of NY, NY County) brought hard municipal service allocation into the environmental realm. Inequalities in such services must be seen as issues in environmental justice.

Table 3 shows that NYC is not a special case. Five of the eight analyzed metro regions show regionalization of TB, i.e. commuting patterns correlate highly with TB incidence patterns. Table 3 also compares regressions of poverty and overcrowding vs TB incidence for Detroit, Philadelphia, San Francisco, Washington, and NYC. Overcrowding affects little of the TB pattern in Philadelphia, an effect which may account for only a trend to regionalization. Detroit has the lowest number of jobs per square mile in the central county and may not be the site of major work-related transmission. The socioeconomic and demographic structure of each metro region determines the strength of regionalization. The housing overcrowding, poverty, and job density of the inner city determines whether regionalization of TB will occur at all. At the regional scale, three types of transmission must occur: household, community, and work-related, loosely meant.

We have used tools from the ecological toolbox to look at pattern of TB incidence and its possible determinants: measurement of diversity, mapping, correlations of phenomena which co-vary within the same geographic area, and changes in geographic patterns over time. A last example applies the Niche Exclusion Model to TB in the 52 CDC designated "states" (the states plus DC and NYC). The Niche Exclusion Model finds the species in an ecological community which compete for the same resources.

Figure 10a displays rank vs the detrended TB incidences for years 1985, 1987 and 1990 for the top 25 states. Figure 10b displays the same data for AIDS. Figure 10c shows the same for measles. Detrending was performed by divided each state's incidence by the average for all 52 states for the given year(incidences from CDC's Annual Summaries of Reportable Diseases for 1985, 1987, and 1990). We know that AIDS is a new epidemic spreading from epicenters. The evening out of the rank vs incidence documents this spread, as more states get drawn into the epidemic process. Measles shows this evening out more strongly. The rise in TB incidence showed the opposite behavior. The highest ranking incidence rose farther and farther above the lower ranked ones. Old large reservoirs simply grew and left the others behind.

Figure 11a graphs rank vs the log of TB incidence for the same years as Figure 10. Figures 11b and 11c show the same for AIDS and measles. In 1985, the latter two diseases had a pattern of little isolated clumps along the plot line, not a single system. By 1990, measles had resolved into a single system and AIDS had nearly resolved into a single system, as shown by a nearly smooth curve. TB, on the other hand, went from a smooth line in 1985 to a series of three or more lines with greatly different slopes. What had been a single system had devolved into several subsystems. The states along these straight lines would be interpreted by the Niche Exclusion Model as "competing" for cases. If cases are the inverse of resources needed to prevent TB, the interpretation would point to competition within these systems for these resources (housing, jobs, working conditions, access to health care, etc.). The steepness of the slope indicates intensity of competition for scarce resources. For an explanation of the Niche Exclusion Model, see Pielou (1975) or Magurran (1988).

A further list of sources for potentially useful approaches and analytical models is appended to this paper. Public health scientists should be encouraged to transfer methods and experiment. We would be happy to serve as resources for scientists willing to try out these methods but wanting some help getting started.

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Appendix: Sources for Ecological Analytical Methods

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Table 1. 1990 New Case Incidence minus 1978 New Case Incidence by Health District

health district	difference	health district	difference
Central Harlem	181.2	Bay Ridge	5
East Harlem	110	Bedford	82.3
Kips Bay-Yorkville	-4.9	Brownsville	34
Lower East Side	87.3	Bushwick	69.5
Lower West Side	26	Flatbush	25.3
Riverside	33.2	Fort Greene	41.2
Washington Heights	37.8	Gravesend	13.5
Fordham-Riverdale	20.8	Red Hook-Gowanus	25.9
Morrisania	93.8	Sunset Park	16.7
MottHaven	70.9	Williamsburg-	
Pelham Bay	21.5	Greenepoint	55.2
Tremont	63.3	Astoria-L.I.C.	36.7
Westchester	17.1	Corona	17.8
		Flushing	10.3
		Jamaica East	31.3
		Jamaica West	15.8
		Maspeth-Forest Hills	5.1
		Richmond	6.2

Table 2. TB Cases Per Sq-Mile by Health District

Health District	1978	1982	1986	1990
Top Five Districts in 1990 for Incidence				
Central Harlem	43	66	82	144
Lower Eastside	29	34	56	89
East Harlem	13	18	48	81
Morrisania	15	18	31	45
Bedford	19	21	35	55
Bottom Five Districts in 1990 for Incidence				
Gravesend	2	5	5	7
Flushing	1	2	1	2
Maspeth-Frst Hills	2	2	2	4
Richmond(SI)	<0.5	1	1	1
Bay Ridge	2	3	3	4
Kips Bay-Yorkville	6	5	7	4

Table 3. Metropolitan Regionalization of TB

A. Percent R-sq and Significance of Regressions without the Travel Center: TB Incidence of the SMSA Counties vs Commuting Index.

The travel center for the NY metro region is Manhattan.

	Boston	NYC	Philadelphia	Washington	Chicago	Detroit	St. Louis	San Francisco
R-sq	52.9	69.8	24	70.8	60.2	10.1	25.3	58.2
significanc	0.04	0	0.11	0.001	0.04	0.49	0.17	0.017

B. Possible Factors for Strength of Regionalization in Five Metro Regions: housing overcrowding, poverty rates, and jobs per sq mi in the travel center. The travel center for the NYC region is Manhattan.

The two regressions are county index of extreme housing overcrowding and poverty rate vs county TB incidence.

	NYC	Philadelphia	Washington	Detroit	San Francisco
R-sq, 1985*	69.4	16.9	79.7	34.6	30.8
R-sq,1985**	68.1	46.5	44.4	27.5	38.8
jobs/sq mi, 1990	71819	5531	11565	1372	11904

*Index of Extreme Housing Overcrowding vs TB incidence
**Poverty Rate vs TB incidence

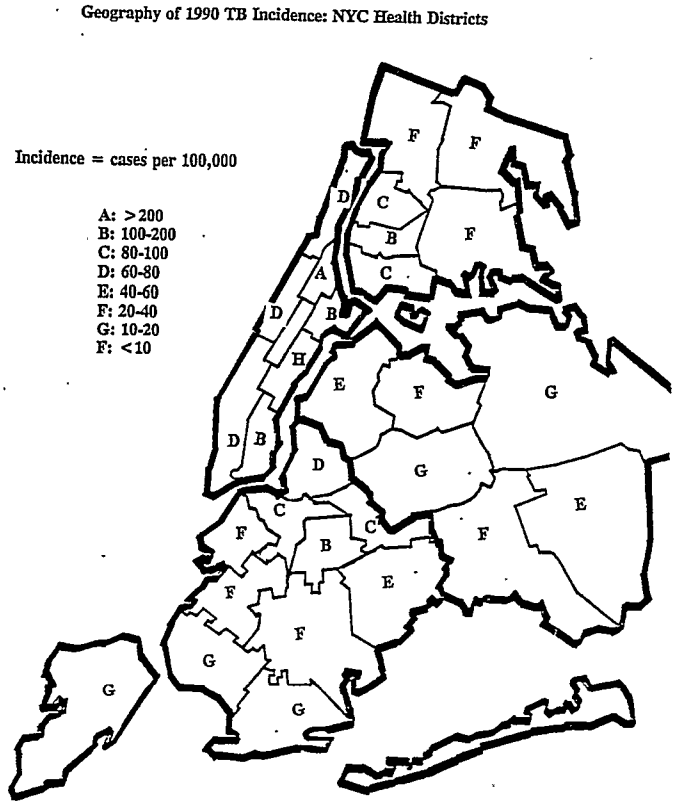


Figure 1. Ranges of Tuberculosis New Cases/100,000 in 1990 of the 30 Designated Health Districts in New York City.

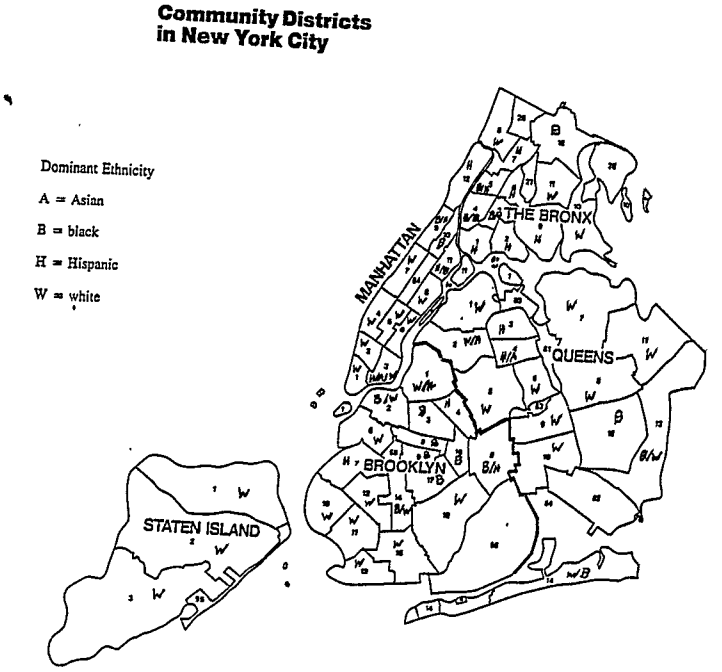


Figure 2. Dominant Ethnicities of the 59 Community Districts of NYC.

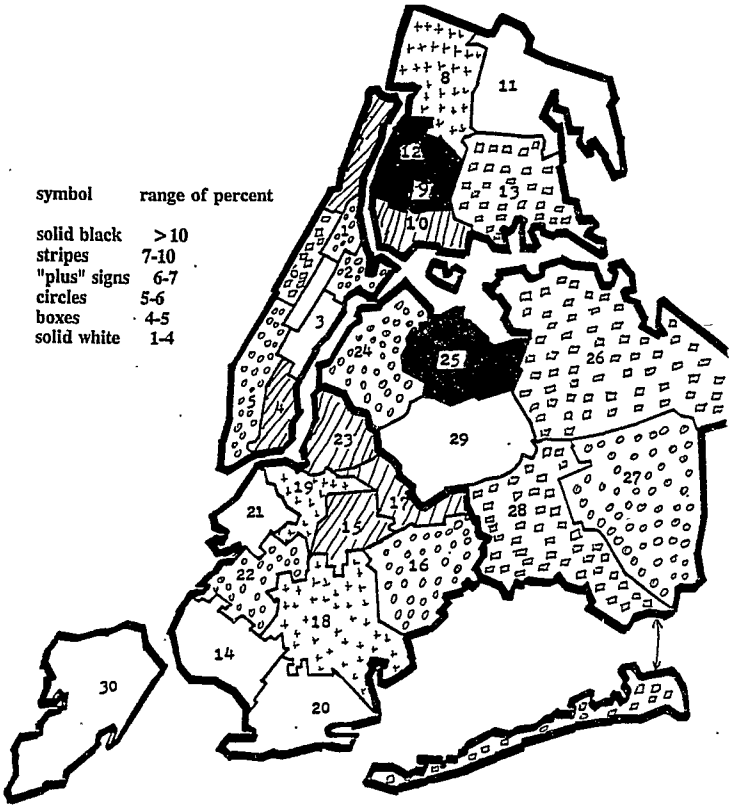


Figure 3. 1990 Ranges of Percent of the Dwelling Units with 1.51 Persons per Room or More of the NYC Health Districts.

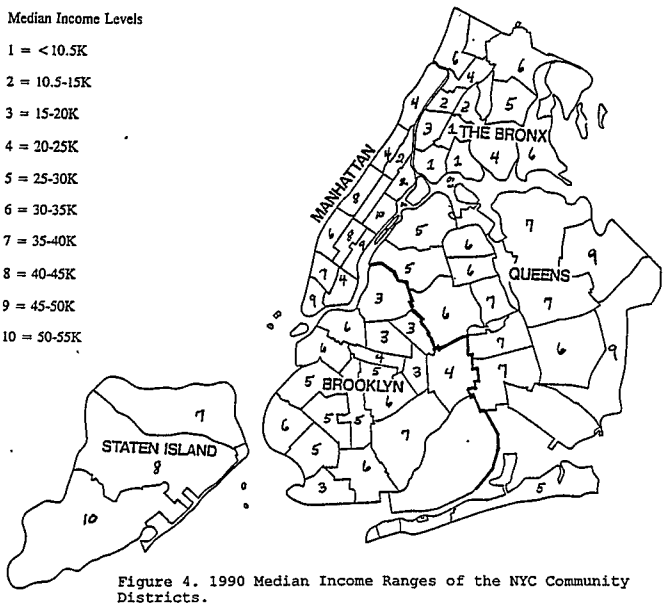


Figure 4. 1990 Median Income Ranges of the NYC Community Districts.

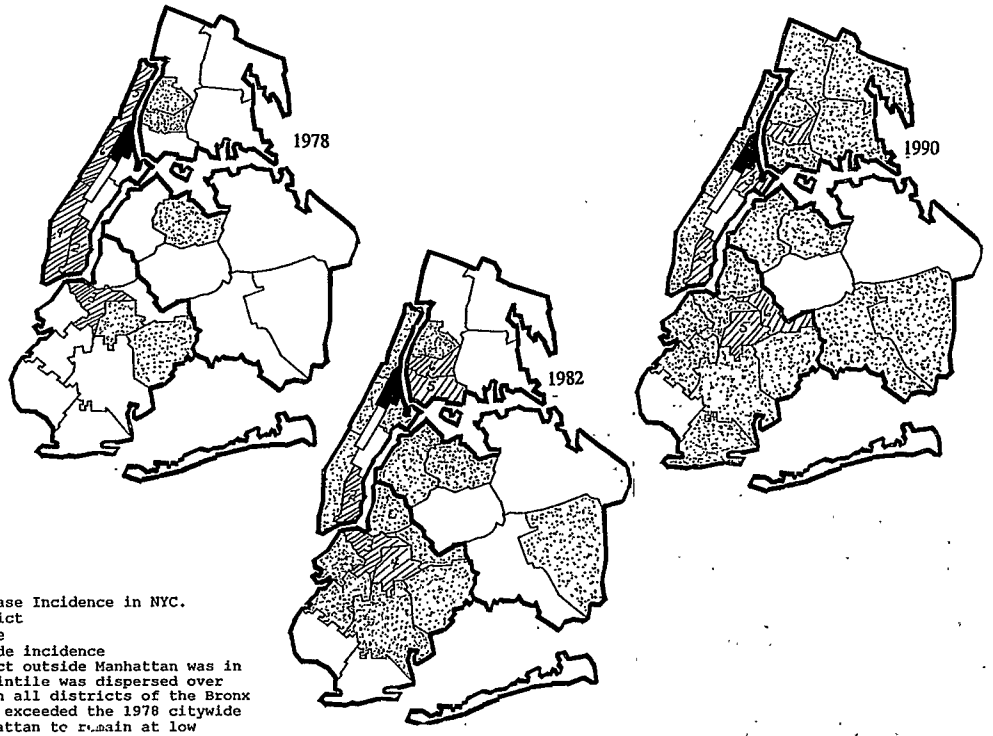


Figure 5. The Spread of High New TB Case Incidence in NYC.
Solid black: top ranking health district
Stripes: other members of top quintile
Stipples: incidence above 1978 citywide incidence
To be noted: In 1978, only one district outside Manhattan was in the top quintile; by 1982, the top quintile was dispersed over three boroughs. By 1990, incidence in all districts of the Bronx and all districts but one in Brooklyn exceeded the 1978 citywide incidence. The only district in Manhattan to remain at low incidence was the wealthiest district in the city. Taken from Wallace, 1994.

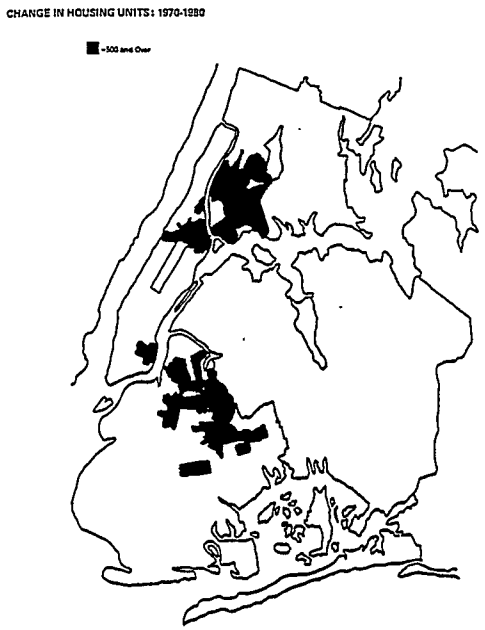


Figure 6. Massive Housing Unit Loss between 1970 and 1980. Each black area is composed of many census tracts, each of which lost over 500 housing units between 1970 and 1980 (Wallace and Wallace, 1990).

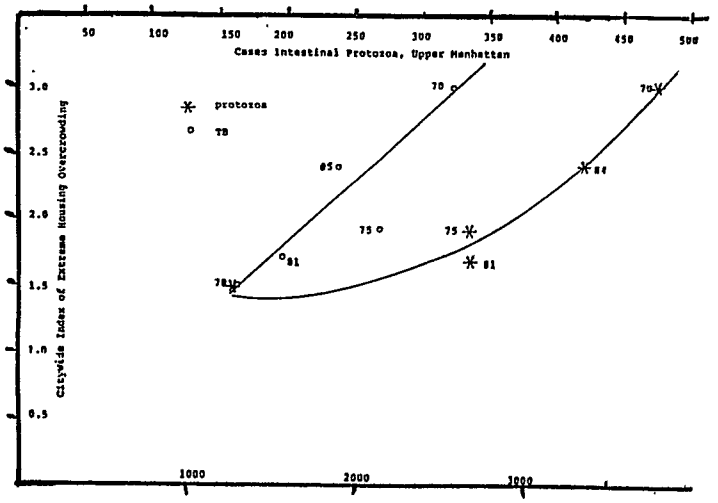


Figure 7. Tuberculosis Cases per Year in NYC vs Citywide Percent of Extremely Overcrowded Housing Units. The circles designate new citywide TB cases and the stars, new cases of intestinal parasites in Upper Manhattan. Taken from Wallace and Wallace, 1990.

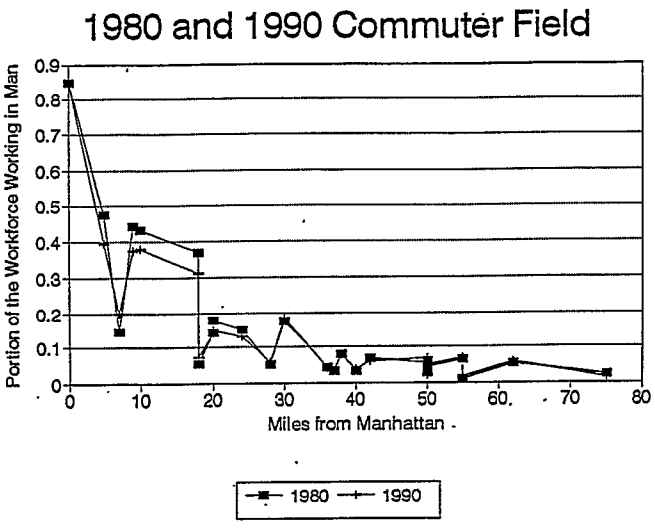


Figure 8. The Commuting Field of Manhattan. Proportion of the workers living in the NYC SMSA counties who work in Manhattan vs. The distance (miles) of the counter center from Manhattan center. Note that Fairfield Cty. (Over 60 miles out) has more than 5% of its resident workers commuting to Manhattan. NYC has an effective radius of >50 miles.

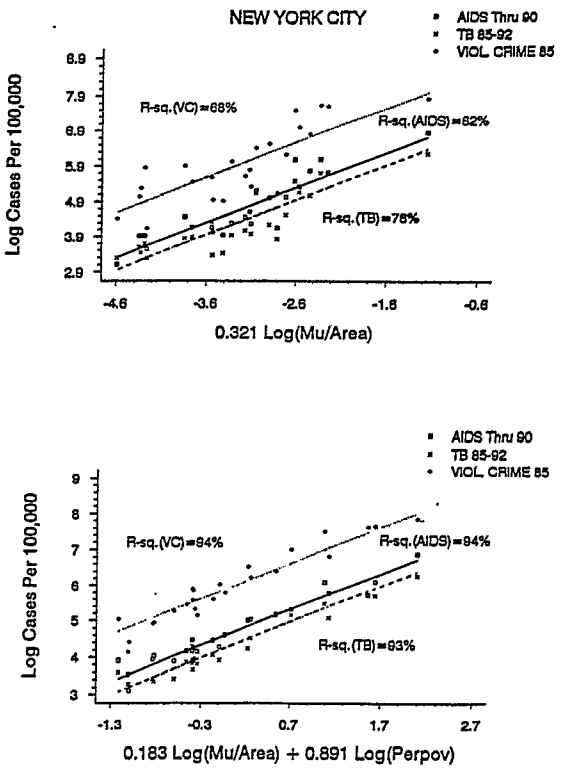


Figure 9. Log of Incidence/100,000 of TB, AIDS, and Violent Crime vs Index of Commuting (24 Counties of the NYC SMSA).
Top graph: Incidence vs only Commuting Index
Bottom graph: Incidence vs Commuting Index and Percent of Population in Poverty
For commuting index, see Wallace and Wallace, 1995.

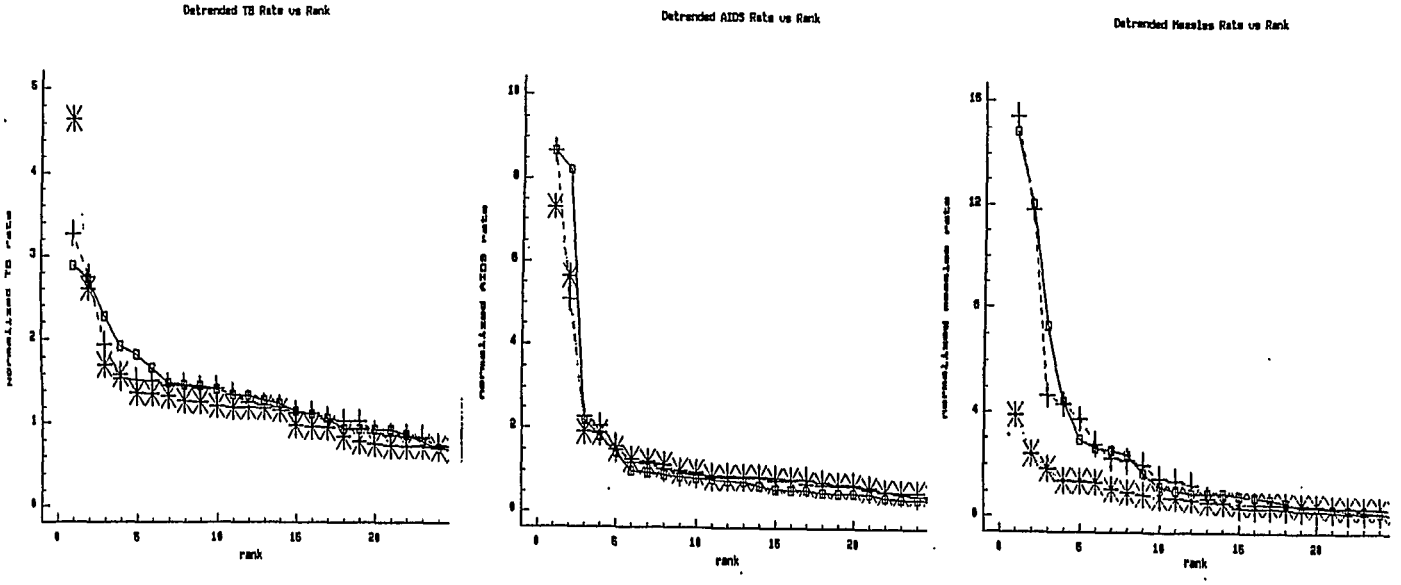


Figure 10. Detrended 1985, 1987, and 1990 TB, AIDS, and Measles Incidence vs Rank for Top Ranked 25 CDC "States". Detrended incidence = state incidence/national mean. Note that for AIDS and measles, the top ranked states in 1990 fell below the 1985 level, especially for measles. Also the "tail" rose by 1990. The opposite occurred for TB.

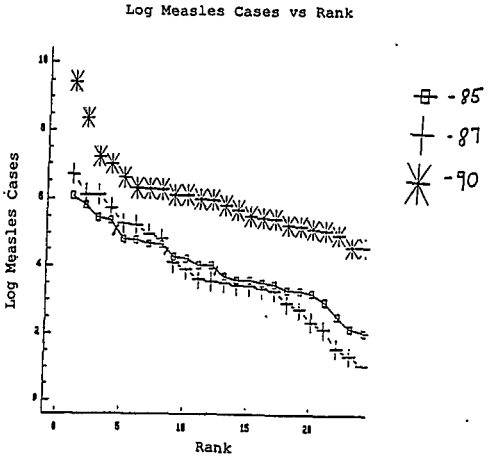
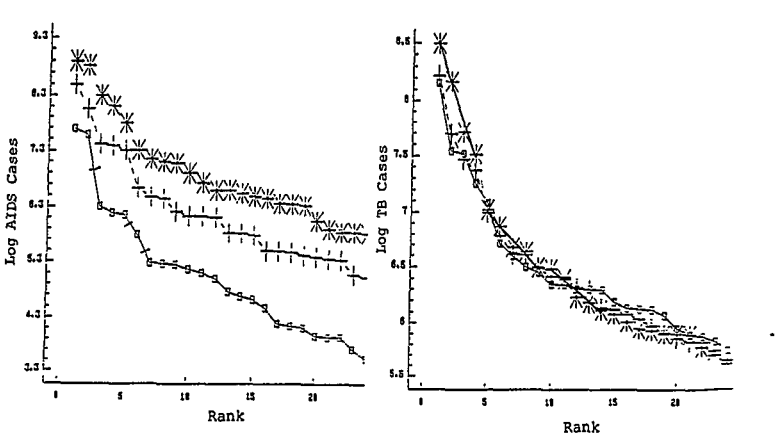


Figure 11. Application of the Niche Exclusion Model to Measles, AIDS, and TB: Log Incidence vs Rank of Top Ranked 25 CDC "States" for 1985, 1987, and 1990. The marks perpendicular to the 1985 AIDS and measles lines bound separate little systems in the upper ranks, especially obvious for AIDS. By 1990, measles had resolved into a single national system, and AIDS was nearly similarly resolved. In 1985, TB was more a single system than in 1990. The heavy lines in the TB graph connect points lying along one line which form a system: ranks 1-4, 5-9, and 10-14.



THE ROLE OF ETHNOGRAPHY IN PUBLIC HEALTH

by Anne Dievler

I. Introduction

I would like to begin my presentation with an interchange between an anthropologist and an epidemiologist:

> An anthropologist starts by saying: "Many people are unhappy with the U.S. health care system and are..." And an epidemiologist interrupts and says: "What people? How many? When do they feel this way? How long have they felt this way? Where do they get their care? What kind of care do they get? What do they need?" So the anthropologist, shrugs her shoulders in frustration and says: "Oh -- Never mind."

While there may be some irreconcilable communication problems between anthropologists and epidemiologists, today I hope to bridge some of that gap as I talk with you about one of the methods that anthropologists use, the ethnographic method. I am going to talk about the role of ethnography in public health and its particular usefulness in understanding urban public health problems.

II. Defining Ethnography

First, I think it is important to have a clear understanding of what ethnography is; so if those of you that are medical anthropologists will bear with me... Ethnographic research is a cyclical and iterative process (Figure 1) (Spradley, 1980; Agar, 1980). One selects a project, develops broad research questions using a conceptual framework, and then selects a site. Then the researcher begins to ask ethnographic questions -- questions not unlike those asked by our epidemiologist friend here -- but questions that are perhaps more sensitive to cognitive processes and the culture of the individuals. In addition to questions of what, how, where, the ethnographer asks, like a two year old: why, why, why?

The ethnographer then collects a wide range of ethnographic data through observing, interviewing, reviewing documents, and makes an ethnographic record -- or "fieldnotes." Next the researcher analyzes the fieldnotes, begins to write the ethnographic story and then reformulates the questions with insights gained from the field and new perspectives from the theoretical literature, and then goes back to the field once again.

Overall, the ethnographic method, while very intensive and time-consuming, can provide rich detail -- and what has been called "thick description" (Geertz, 1973).

I would like to emphasize two things about this research cycle. One is that the conceptual framework is very important -- for example, in studying urban problems -- it would be good to have some theories about urbanization -- whether it is the deindustrialization of cities or the urban underclass -- or if one is looking at urban policy making, it would be important to look at what the literature says about urban policy making. In my experience in public health, we are often weak on the theory side of things.

I would also like to emphasize that the ethnographic write-up is very important. The write-up, also called an "ethnography," is shaped by the author's theoretical orientation and the narrative and rhetorical conventions he or she chooses to employ.

III. What is the role of ethnography in public health?

The best way to approach this question is to look at the core public health functions defined by the Institute of Medicine, assessment, assurance, and policy development, and to see how ethnography applies to each area.

A. Assessment

With the assessment function of public health, we try to understand health problems and assess the needs and health status of the population.

Many of the most pressing urban public health problems: violence, teen pregnancy, substance abuse, TB, and HIV/AIDS are complex problems that are intertwined with social and economic conditions such as poverty, homelessness, and unemployment.

Because ethnography takes a holistic and contextual approach to problems, it can help us to understand these problems better. Armed with epidemiology and biostatistics, public health professionals usually select a sample, develop a questionnaire, administer and then analyze it. Ethnography can help us to figure out if we are asking the right questions and if we are asking them in the right way.

Ethnography has also been practical in helping to enumerate populations. For example, you are all familiar with the fact that the 1990 census was criticized for resulting in an undercount of the population, particularly in urban, inner city areas. So the Census Bureau hired anthropologists who went out and estimated the extent of the undercount, and the causes of the undercount, and did a reenumeration. As a result, fundamental changes were made in the way the Census Bureau will carry out the year 2000 population survey.

B. Assurance

The assurance function of public health has to do with assuring that people have access to care and that they get quality care.

In the field of medical anthropology, there has been extensive research on the individual, doctor-patient relationship and the quality of care that patients receive in health care settings. I think there has been less application of ethnographic methods to the system of health care.

Recently I came across a wonderful ethnographic account of the failure of urban health care entitled: *Mama Might be Better Off Dead* -- by Laurie Kay Abraham (1993). Abraham is actually a journalist, but like an ethnographer, she spent three intensive years chronicling the lives of a sick, poor family in Chicago and the institutions that served or

failed to serve them. As a result, she provides a stunning indictment of the U.S. health care system. I think public health would benefit from more analyses of this kind.

C. Policy Development

Finally, how useful is ethnography in studying the development and implementation of public health policy by local, state, and federal public health agencies and the community agencies they work with?

Ethnographic methods have been used since the 1930s and 1940s in the U.S. to understand the culture and operation of organizations, from the classic Hawthorne studies, to studies of public sector bureaucracies such as Philip Selznik's study of the Tennessee Valley Authority.

In my own work, I used ethnography to study the development and implementation of public health policy in an urban bureaucracy, the Washington, D.C. Commission of Public Health.

I started out with some broad research questions -- I wanted to know:

Why is public health in some areas, particularly urban areas, in disarray?

How are policies being formulated and implemented by the government to address major urban public health problems? and

What is the role of rational planning in policy making?

From these broad questions, I selected the D.C. Commission of Public Health as the site for my study, and I also selected three cases: HIV prevention, tuberculosis control and childhood immunization.

I then began asking ethnographic questions and doing my fieldwork. The whole process continued for almost two years. As I engaged in this ethnographic research, I relied heavily on literature from the fields of public administration and political science; because early on, I recognized that rational planning was not driving the policy making process, but rather what was important was the nature of the bureaucracy and the political process.

I found that the problems that I studied: HIV/AIDS, TB, and childhood diseases are persistent, complex, and difficult for policy makers to solve. Instead of being a rational process, policy making was slow, incremental, reactive, and even erratic. Technical, bureaucratic, and political factors shaped how problems were defined, whether they got on the government's agenda for action, what strategies were developed to respond to the problem, and whether or not those strategies were implemented.

For me, using ethnographic tools was a way to try to make sense out of a very complicated policy process. Hopefully, my ethnographic write up -- which I did in the form of case studies -- will also be useful in promoting understanding about why public health is in disarray and what can be done to strengthen the capacity of our public health institutions.

IV. Conclusion:

I would like to conclude by drawing your attention to a recent article by Marcia Inhorn in *Social Science and Medicine* (1995). Inhorn points out that there are, in fact, many areas of convergence between the fields of anthropology and epidemiology in terms of views of health and disease, observational approaches, and the broad, interdisciplinary nature of inquiry. Both fields are rooted in the tradition of understanding how the well-being of individuals is directly affected by their physical, social, cultural, and even political environments.

The pressing problems of urban areas require that we be as creative as possible with our methods, and I think that ethnography can compliment many of our traditional epidemiologic approaches and provide new insights in public health.

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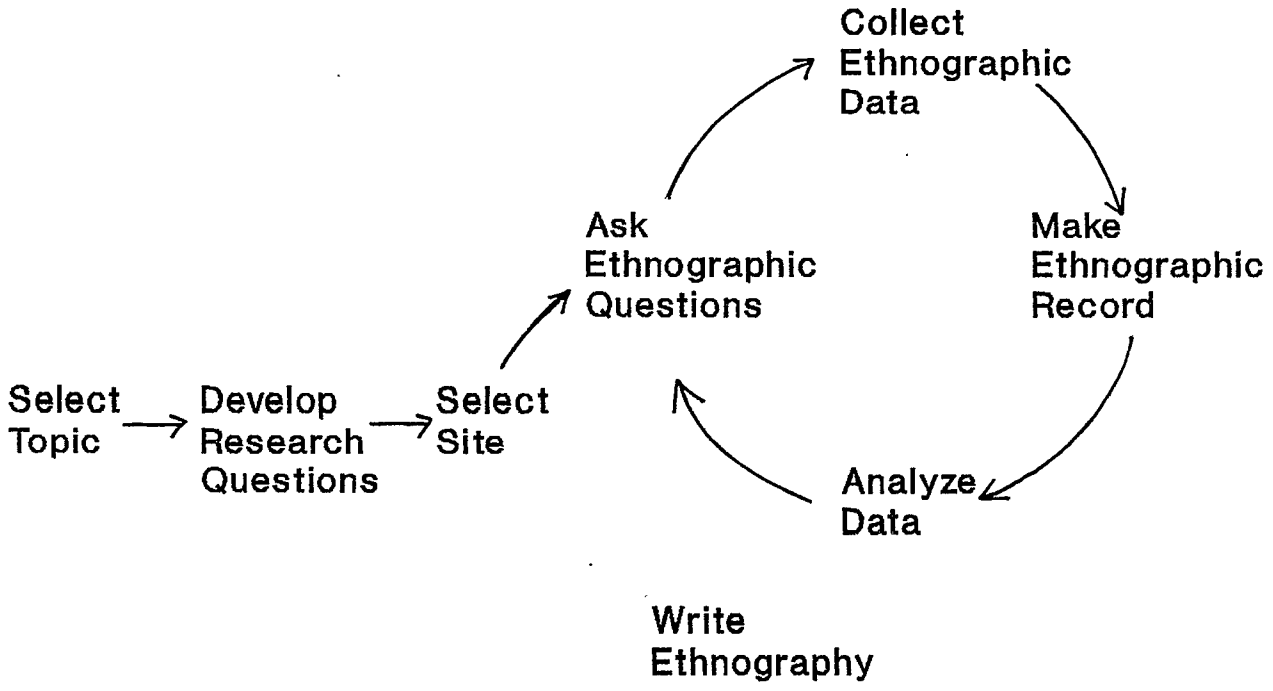
Figure 1

Ethnographic Research



METROPOLITAN AREA DATA BASES FOR PUBLIC HEALTH ASSESSMENT

Dennis P. Andrulis, National Public Health and Hospital Institute

Paper not available for publication.

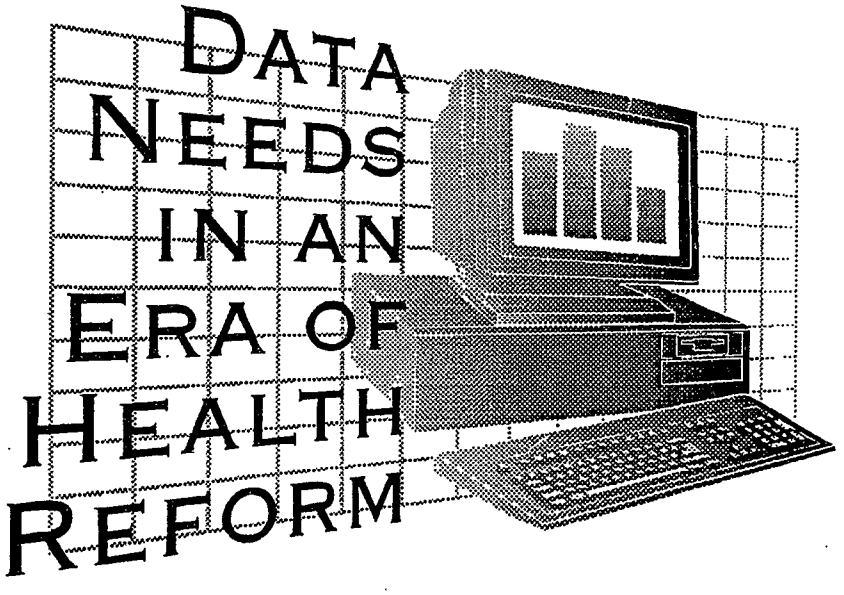
IDENTIFICATION OF DATA NEEDS TO ADDRESS THE URBAN HEALTH CRISIS: A POLICY PERSPECTIVE

Robert E. Fullilove, Columbia University School of Public Health

Paper not available for publication

Session L

Measuring Neighborhood Effects on Health



EXAMINING ALTERNATIVE MEASURES OF UNDERSERVICE

Thomas C. Ricketts, Ph.D.
University of North Carolina at Chapel Hill
Donald H. Taylor, Ph.D.

The federal government and most states use some form of indicators to identify areas, populations, or institutions as medically underserved in order to prioritize the allocation of programs or resources. The current, most commonly used measures have been criticized as not being precise enough in identifying underservice or as being inappropriate for the programs which use them. This study used a theoretical model to construct alternative measures of underservice applicable to whole U.S. counties. One of the new, alternative measures identified 657 whole counties as underserved, this approximates the number of Health Professional Shortage Area (HPSA) designations (717) for 1990. This alternative measure was also compared with the HPSA and the Index of Medical Underservice (IMU) on its ability to identify areas in which respondents to the National Health Interview Survey were more likely to report access problems or lower health status. The alternative measure performed as well or better than the HPSA or IMU in predicting individual problems with access and need.

In order to target assistance to reduce medical underservice (defined as systematic access barriers to primary care), the federal government has relied upon the Health Professional Shortage Area (HPSA), and the Index of Medical Underservice (IMU) methodologies to identify areas eligible to receive assistance under various programs meant to improve access to health care. However, the continued use of both the HPSA and MUA methodologies has been criticized over the past 15 years on four main fronts:

(1) areas designated by these methods do not differ from areas not so designated on key outcomes such as physician visits and health status;
(2) they lack sufficient theoretical justification and basis;
(3) they do not clearly define what it is they seek to measure; and
(4) they are used to designate areas as eligible for programs not related to the original intent of the measures.

These critiques are causing policy makers to explore the potential for the combination of the HPSA and IMU into an improved measure or to create new measures that are applicable to specific program needs. in developing new identification of problem areas. The Health Resources and Services Administration has been studying both the HPSA and IMU methodologies for the past 2 and 1/2 years with a view toward developing a single methodology for use with all federal assistance programs aimed at improving access in local areas.

In the project describe here, a research team at the University of North Carolina has undertaken a comprehensive review of the use of the HPSA and MUA methodologies and developed several alternative measures of underservice. The first year of our review of the HPSA and IMU methodologies produced the following conclusions:

1. There are some conceptual problems with both the HPSA and MUA methodologies, but changes made to them could have large consequences.

2. Definitions of 'underservice' and 'provider shortage' should be made clear when developing any new methodology.

3. Policy goals of programs should fit the definition of underservice/provider shortage adopted to designate areas eligible for programmatic assistance.

4. The unit of analysis for these types of methodologies may begin to shift away from counties or other localized geographic areas and toward population access to a larger health care delivery system that may be geographically dispersed.

5. The biggest practical issue for any methodology is what data are needed and who is responsible for designation of areas as eligible for assistance using the methodology.

6. Any change in methodology for designating eligible recipients for assistance will probably create winners and losers, making any change politically difficult.

These 6 conclusions formed the starting point of our efforts to develop an alternative means of designating counties as medically underserved. Our efforts to develop an alternative means of designation were guided by clearly defining the term, suggesting a conceptual model of medical underservice, and testing several representations of this model with LISREL® using 1990 county level data from the Area Resource File. Respondents to the 1990 National Health Interview Survey (NHIS) living in counties designated as medically underserved by each of the designation methods are compared to those respondents living in counties not so designated in order to determine if they differ on several measures of access and need. This research produced five alternative measures of medical underservice (The Taylor Indices of Medical Underservice) that have been compared to each other as well as the HPSA methodology and the IMU.

Policy Review

Since their introductions in 1974 (IMU) and 1978 (HPSA), the two indicators have undergone some minor changes in their structure but they remain basically the same as when they were first applied. The HPSA measure has been changed formally by legislation and regulation to include a prioritization process while the MUA has remained essentially a ranking system for counties with a liberal cut-off level for qualification as a medically underserved area. The HPSA depends largely on the physician-to-population ratio but the threshold level of one

primary care physician to 3,500 people in a "rational medical service area" can be modified down given high levels of need indicated by infant mortality or other factors. The HPSA designation process has been largely a locally-initiated process with the federal Division of Shortage Designation responding to applications and requiring areas to re-apply after three years of designation. The Division was reported to have significant lag times in the application and appeals process during the recent past but has cut turn-around time for decision to 30 days in most instances. The designation process created a need for a response on the part of state and local level officials who sought designation to support needed primary care services in selected communities. Officials in certain states and localities became adept at identifying and supporting applications with timely and appropriate data while other localities were unable to cope as effectively with the process. This created a situation where certain areas of the nation were more likely to have designations than others independent of the local situation.

The number of areas designated as MUAs remained fairly stable over the period 1974 to 1995; there has not been a comprehensive designation of counties since 1981 and fairly few changes in the listing of MUAs are made every year through application to the Division. There has been substantial changes in the number of HPSA areas, populations, and facilities designated with a steady upward trend in the total appearing since 1990. A significant number of designations have been continuous or "chronic." Fifteen percent of 352 Nonmetropolitan and four percent or 30 metropolitan counties have been designated every year since 1978. Another 458 partial Nonmetropolitan and 259 metropolitan counties have been designated more or less permanently. Seven hundred forty-seven counties or 24 percent of all counties have never been designated.

Table 1

	Nonmetro Number (%)	Metro Number (%)
Chronic Whole	353 (15%)	30 (4.1%)
Chronic Partial	458 (19.5%)	259 (33%)
Non-Chronic	997 (42.5%)	250 (33.8%)
Never Designated	535 (22.8%)	212 (28.7%)
Total	2343 (100%)	751 (100%)

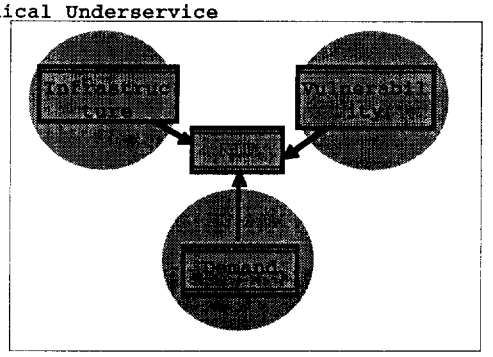
The MUA is a score assigned to areas based on four factors: Population-to-primary care physician ratio, population over 65, infant mortality rate, and percent of population below poverty. The scoring system assigns an inverse weight to each item for a county or a designated area and those areas which have a score of 62 or less are designated. The MUA designation is not parallel to the HPSA, in 1980 123 Nonmetro and 6 Metro counties were below 62 but not HPSAs. In 1990 these numbers dropped to 82 Nonmetro and no Metro counties.

Construction of a Theory Based Measure of Underservice

The second year of the project began with a review of general literature on need and utilization of primary health care as the basis for the development of a theoretical model of underservice. The literature pointed to three general factors that could be measured at the community level as describing underservice: Infrastructure, Vulnerability, and Demand. Community level variables were used to confirm the existence of these factors. Examples of the variables used include, for Vulnerability–percent of population over 65, mortality rates, percent below poverty, per capita income; for Infrastructure–primary care providers, medical specialists; and for Demand–percent population college educated, percent with white collar jobs. For the purposes of this project, all of the variables related to the individual county since these data were the most readily available and all variables were drawn for the year 1990. The project recognized that rational service areas were often parts of counties or multiple counties and that the data analysis process was one of estimation and approximation.

A model containing the three factors believed important in defining underservice was estimated using the LISREL (structured equations) technique to obtain quantitative estimates of the degree of "fit" between the health system (Infrastructure) and the local population (Vulnerability and Demand). The degree of "fit" between these is the indicator of medical underservice used to identify places where access may not be adequate.

Figure 1: Conceptual Model for Determination of Medical Underservice



The model depicted above produced a county level score for "fit" that was then scaled, this results in a relative measures of "service" or access–counties that fell into the bottom quartile for Nonmetropolitan and the bottom decile for metropolitan counties on the Fit score were classified as "underserved." These cut points were chosen because they approximated the cut-points used in scales to determine underservice in the HPSA and MUA systems. These criteria identified 73 metro and 584 Nonmetro counties as underserved for a total of 657 counties. This compares to a total 717 HPSA and 757 MUA whole counties designated in 1990. The overlap is illustrated in Table 2.

Table 2

	FIT Model	**IMU 1990**	**HPSA 1990**	**HPSA 1992**
FIT Model	657			
IMU 1990	430	757		
HPSA 1990	379	422	717	
HPSA 1992	380	421	588	722

The designation pattern based on FIT identified several geographic areas where communities may not have been aggressive in obtaining HPSA designation. Areas of central Kentucky, west Texas, northern Missouri and southern Iowa were

identified by the FIT method as being potentially severally undeserved but not designated as HPSAs.

Comparison of FIT, HPSA and MUA designations and Population Based Measures of Underservice

There are no locally applicable and consistent measures of population based access or underservice with which to verify the accuracy of the FIT designation, or, for the HPSA and MUA process. National health status and perception surveys are based on cluster sampling and are meant to be used to characterize the nation or large regions, occasionally statistics can be drawn for large states or for cities. In order to compare the performance of the various measures of underservice with these national surveys, geographic identifiers have to be attached to the individual respondents and the data aggregated into groups for those respondents living in areas designated by one or more of the measures. This was done using the 1990 National Health Interview Survey for which the National Center for Health Statistics allowed access to the individual, geo-coded records under a special agreement.

Within the question structure of the National Health Interview Survey, there is no single indicator nor is there an apparent cluster of indicators that would serve as a proxy or measure for access or underservice. The analysis then was to determine the relative levels of correlation between the three methods (FIT, MUA, and HPSA) and various indicators thought to be related to underservice. These included restrictions on activity, presence of chronic conditions, self-report of poor health, and use of physician services. The analysis also included measures of intervening variables generally thought to affect access and which are directly related to utilization and other indicators of outcomes which were not measured in the survey; these included race, income, and education.

The analysis revealed that the persons living in HPSA, MUA and FIT designated areas had approximately similar characteristics and those characteristics identified them, generally, as being more underserved than people not living in the designated areas. However, the responses of those living in areas designated as underserved did not differ significantly from those living in areas not designated. In particular, consistent differences in the use of physician services were not found. This agrees with earlier research that has generally concluded that the HPSA and IMU do not do a particularly good job of differentiating areas with access problems from those without. These measures do appear to identify people with health care needs and different health status but they do not correlate well with the indicators of utilization which is often considered a reliable indicator of access.

Conclusions

1. There are objective, theory driven ways to identify variations in areas.

2. Alternative Method C performs slightly better than HPSA and MUA in identifying populations with "structural" or access problems.

3. The methods developed are not appropriate for metropolitan areas, where the county as unit of analysis is too large.

4. Data availability, particularly the unit of analysis that is available, is a large factor in determining the ability to make changes in the present means of designating local problem areas.

EFFECTS OF LIVING IN A POOR OR UNDERCLASS NEIGHBORHOOD ON CANCER SCREENING

Janis Barry Figueroa, Fordham University
Nancy Breen

Neighborhood-level factors may preclude access to health-care resources or the ability to utilize relevant new medical knowledge, contributing to small-area variations in health outcomes. We test whether four residential indicators explain variations in diagnostic-stage among women with cervical and breast cancer.

Previous studies have found that socioeconomic status (broadly defined) plays a significant role in determining cervical and breast cancer screening, diagnosis and survival (Burg, et. al., 1990; Farley and Flannery, 1989; Funch, 1986). We examine whether Census tract measures of economically and socially declining inner-city areas increase a number of risk factors that are associated with a later-stage diagnosis of breast and cervical cancer. Our study implicitly considers how neighborhood-level factors lead to later-stage diagnosis through the underutilization of screening services by medical providers and/or women seeking care. We stress neighborhood attributes that both influence individual behavior and undermine the capacity of institutions such as schools or health clinics to be responsive to the needs of the community. Inner-city neighborhoods have less access to markets. We would expect the quality and quantity of health care services used in these areas to vary according to physician advice and the valuations given to preventive care by community residents (Barry Figueora and Breen, 1995).

The lack of routine collection of socioeconomic data on medical records, disease registries and other vital statistics has limited the ability to identify the causal process through which the social environment influences health outcomes (Krieger, 1992). For example, the best data on individual cancer incidence and type, is available from the SEER (Surveillance, Epidemiology, and End Results) program. However, it does not collect data on individual income, occupation, education and health care coverage. Therefore, we use Census tract-characteristics to augment SEER data.

RESIDENTIAL LOCATION AND CANCER DIAGNOSIS

Rather than using census-tract data as a proxy for individual attributes, we use area data to demonstrate the importance of neighborhood characteristics. The urban underclass literature suggests that cultural, economic, social and technological change have connected the fates of individuals and families living in the inner-city to their communities (Mincy, 1994). High-risk, urban neighborhoods characterized by vacant housing, small-business abandonment, poor schools, violent crime, illiteracy, and disease reflect, in part, the inadequacy of social support networks in the face of concentrated and persistent poverty. We assume that the demand for health care is affected by residential segregation and isolation from mainstream institutions in neighborhoods where income is derived from sources other than work in the formal economy (Wolfe, 1994).

The "underclass" and "severely distressed" neighborhood indicators transcend standard disciplinary definitions. They include both geographic (spatial concentration of poverty in urban areas), economic (employment rates) and social-cultural factors (rates of unmarried motherhood) that distinguish them from measures of either income or behavior alone.

DATA AND METHODS

In our model the binomial dependent variable measures the likelihood that women are diagnosed after the tumor is invasive (1=invasive). We analyze cases of breast and cervical cancer diagnosed between 1989 and 1990 that could be matched with Census-tract data in the Atlanta, Detroit and San Francisco SEER program areas.[1] These three cities were chosen because they are major metropolitan areas with both high- and low-income Census tracts and racially and ethnically diverse populations. Independent variables include individual measures of race (non-Hispanic white=0), age, marital status (married=0), and city of residence (San Francisco=0). Key independent variables are matched Census-tract indicators of residency in an underclass (=1), an extremely poor (=1), severely distressed (=1) or in a medically underserved area (=1). The underclass measure, developed by Ricketts and Sawhill (1988) flags a Census tract if all of the following proportions are at least one standard deviation above the national mean: (i) 16-19 year-olds not enrolled in school and not high school graduates, (ii) males aged 16 and older out of work for more than 26 weeks, (iii) households receiving public assistance income and (iv) female-headed households with children. Our poverty measure, developed by Jargowsky and Bane (1991), groups Census tracts into three types: (i) less than 20 percent of households in poverty, (ii) between 20 percent and 40 percent in poverty, or (iii) more than 40 percent in poverty. Severely distressed neighborhoods are those underclass tracts that in addition, register at least one standard deviation above the national tract mean on the proportion of the

resident population below the poverty line (Kasarda, 1993).

The federal government designates an area as medically underserved (MUA) when the following four-variable index exceeds a specified benchmark: the ratio of primary medical care physician-to-population, the infant mortality rate, the percentage of the population with incomes below the poverty level, and percentage of the population over age 65 (Code of Federal Regulations, 1993 Ch 1 [Appendix C]).

Using logistic regression to analyze each cancer site separately, we estimate whether residence in an underclass, extremely poor, or severely distressed tract is significantly associated with later-stage cancer diagnosis. We expect that women who live in these areas will be more likely to receive later-stage diagnosis than women who do not, ceteris paribus. Furthermore, we expect that the underclass and severely distressed measures will have greater explanatory power than the pure, income-based, poverty measure in predicting diagnostic stage.

RESULTS

Approximately 19 percent of the cervical cancer tumors and 87 percent of the breast cancer tumors were diagnosed as invasive. Three percent of women diagnosed with later-stage breast cancer and 5 percent with cervical cancer lived in underclass areas while 4 percent and 6 percent, respectively, lived in extremely poor tracts. Nine percent of the breast cancer and 11 percent of the cervical cancer cases lived in medically underserved areas.

Table 1 presents the variable proportions. Table 2 gives the logistic point estimates for the breast and cervical cancer models. The scale factor given in the first row is the density function evaluated at the means of the variables (Green, 1994). In brief, the underclass and severely distressed indicators reveal consistently positive and significant effects on later-stage diagnostic probabilities. In the breast cancer sample, probabilities of later-stage diagnosis were increased by 4.3 percent and 4.4 percent, respectively, if the individual resided in an underclass or severely distressed neighborhood. In the cervical cancer sample, the probabilities of later-stage diagnosis were increased by 5.5 and 6.6 percent, respectively, if the individual lived in an underclass or severely distressed area. Residence in an extremely poor tract was a significant explanatory variable only in the cervical cancer sample increasing later-stage diagnostic probabilities by 4.5 percent.

Other findings for the breast cancer sample showed that the probabilities for later-stage diagnosis were 1.7 percent less for women in Atlanta and were 1.8 percent more for women living in Detroit as compared to women in San Francisco. Living without a spouse and yearly age increases elevated later-stage diagnostic probabilities by 1.4 and one-tenth of a percentage, respectively.

The cervical cancer sample revealed increased probabilities of later-stage diagnosis among women living in Atlanta (about 4%) and women living in Detroit (about 3%). Race and ethnicity were significant explanatory variables with black non-Hispanics facing increased probabilities of 3.5 percent (columns one and three), and Hispanic women facing increased probabilities of 4.7 percent (columns one and three). Age was a significant predictor of diagnostic stage, but marital status was not.

DISCUSSION

The spatial concentration of social disadvantage as measured by the underclass and severely distressed indicators, outperformed the income-based, poverty measure in explaining diagnostic outcomes. Social (family instability and low education levels) and economic distress (labor force detachment and reliance on public assistance) at the neighborhood-level are likely to interact in ways that both influence and constrain individual investments in health and use of the health-care system. Moreover, health care markets are not oriented toward servicing physically isolated and socially disadvantaged locales, so that opportunities for early diagnosis of these cancers are lost.

The MUA variable, which marks a shortage of health-care services in poor and elderly communities, was consistently insignificant. This may be due partly to the fact that clinics set up as a result of the MUA designation vary considerably in the range of services they provide, especially cancer screening and treatment. The poor also may face barriers to timely medical care that are not simply a matter of access to health-care services. In the case of cervical cancer, even after controlling for neighborhood effects, the city of residence, and racial and ethnic identifiers remained important determinants of later-stage diagnosis. This suggests the need for continued research on special populations and specific regions of the United States when designing cervical cancer prevention programs.

The study of neighborhoods can motivate a broader integration and synthesis of the literature on socioeconomic status and health. It can also challenge the existing research by raising questions about the links between the financial and behavioral explanations for health outcome inequalities. Further investigation of why individuals do not get the preventive care they need awaits the collection of individual-level social

and economic data on medical data bases. Systematic differences between the average health status of people by region or geographic locale signal that space and place information should be included when analyzing individual determinants of health.

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1.The SEER (Surveillance, Epidemiology, and End Results) program reporting areas may differ slightly from standard Census metropolitan area definitions.

Table 1

SAMPLE PROPORTIONS OF EXPLANATORY VARIABLES

Independent Variable	Breast Cancer	Cervical Cancer
Later-Stage Diagnosis	.871	.185
Atlanta	.183	.197
Detroit	.424	.457
Black/NH	.148	.194
Hispanic	.026	.060
Asian/PI	.032	.025
Age (mean)	61.1	37.5
UnMarried	.465	.559
Underclass	.029	.047
Poverty<40%	.143	.194
Poverty>40%	.043	.062
ServDistres	.026	.043
M.U.A.	.086	.114

SOURCE: 1989-1990 SEER reporting areas for Atlanta, Detroit and San Francisco and 1990 Census Summary Tape Files 3A.

Table 2 Logit Estimates of Stage of Diagnosis Equations, Breast and Cervical Cancer

	Breast			Cervix		
Independent Variables	(1)	(2)	(3)	(1)	(2)	(3)
$\frac{dP(Y=1)}{dX_i}$ [1]	.1110	.1111	.1096	.1218	.1215	.1220
Atlanta	-.156*	-.160*	-.158*	.346**	.326*	.341**
	(2.18)	(2.23)	(2.20)	(2.89)	(2.72)	(2.85)
Detroit	.171*	.169*	.169*	.279*	.245*	.267*
	(2.78)	(2.72)	(2.76)	(2.77)	(2.39)	(2.64)
Black/NH	.089	.069	.092	.295**	.210*	.291**
	(1.08)	(.763)	(1.12)	(2.85)	(1.84)	(2.82)
Hispanic	.168	.167	.171	.393*	.365*	.389*
	(1.00)	(1.00)	(1.02)	(2.23)	(2.05)	(2.20)
Asian/PI	-.011	-.015	-.012	.245	.222	.240
	(.076)	(.105)	(.086)	(1.05)	(.956)	(1.03)
Age	.015**	.015**	.015**	.074**	.074**	.074**
	(8.01)	(8.01)	(8.01)	(28.1)	(28.2)	(28.5)
UnMarried	128*	.127*	.128*	-.018	-.028	-.021
	(2.30)	(2.28)	(2.30)	(.229)	(.349)	(.255)
Underclass	.394*	-	-	.455*	-	-
	(1.99)			(2.60)		
Poverty<40%	-	.087	-	-	.150	-
		(.811)			(1.14)	
Poverty>40%	-	.085	-	-	.376*	-
		(.502)			(2.13)	
ServDistres	-	-	.410*		-	.541**
			(1.93)			(3.02)
M.U.A.	.096	.075	.100	.071	-.022	.073
	(.910)	(.670)	(.956)	(.567)	(.349)	(.589)
Constant	.867**	.869**	.867**	-4.88**	-4.86**	-4.87**
	(7.24)	(7.24)	(7.24)	(32.8)	(32.6)	(32.7)
-2 X Log Likelihood	10157	10157	10157	4116	4116	4116
N of Cases		13398		5401		

[1]Multiply this value times the coefficent estimate to get the marginal contribution of each explanatory variable to the probability of late-stage diagnosis.

NOTE: Dependent Variable: Probability of individual woman being diagnosed with late-stage breast or cervical cancer. T-ratios are in parentheses. *p < .05; **p < .01.

SOURCE: 1989-91 SEER reporting areas for Atlanta, Detroit and San Francisco and 1990 Census Summary Tape File 3A.

ASSOCIATION OF HOUSING AGE AND CONDITION WITH BLOOD LEAD LEVELS

David Gemmel. Western Reserve Care System and Kent State University.

Introduction

As scientific evidence about the effects of exposure mounts, low childhood lead levels have been reclassified as toxic.[1] The Centers for Disease Control and Prevention considers lead levels greater than 10 micrograms per deciliter unacceptable.[2] Although some states require screening of all children under 6 years of age, controversy over the need for universal screening has erupted.[3,4]

Arguments against universal screening include low prevalence of lead poisoning, lack of efficacious treatment for slightly elevated lead levels, and false.positive rates for capillary samples.[3,5] However, low prevalence rates represent large numbers of children effected by plumbism, and population-based prevalence studies are rare.[6] Efficacy of treatment for elevated lead levels has been established and sensitivity and specificity of pediatric lead testing has been evaluated.[7,8] Local communities lack data for targeting.

Epidemiological research offers evidence for targeting. Children at greater risk include inner city residents, the poor, minorities, and children residing in deteriorated housing.[9,10] The risk of lead poisoning in older dwellings has been reiterated.[11-17] Cincinnati researchers found moderate correlations between blood lead levels and housing age.[18] Lead levels in 6-month-old children differed by housing categories, with levels highest in pre-World War II deteriorated housing.[19] Housing age has also been strongly associated with breast milk lead.[20]

Despite this evidence, measurement and analysis of the relationship between lead and housing is often flawed. Categorization of year of structure is misleading and may influence variance estimation. The age, type and quality of a community's housing stock may differ within the same region. Interaction effects either have not been investigated or have not been reported.[21] Since geometric means are lower than arithmetic means, the latter over estimates exposure. The distribution of lead is non-gaussian, and failure to use data transformations underestimates variance. As Dabeka and the World Health Organization have recommended, geometric means are a preferred method to represent lead data.[20,22]

For targeting lead screening activities in Mahoning County, Ohio, a population based prevalence study was conducted to determine the association of housing age and condition with childhood blood lead levels.

Methodology

Subjects

To obtain age of dwellings, birth certificate addresses of children residing in Mahoning County were matched to county auditor data for births between February 1992 and February 1993. Mothers included in the study were those living continuously in the same house since the birth of the study child. Initial phone contact using a reverse or city directory began in January 1994. Households which were not listed were contacted by mail on at least two attempts. Mail carriers also identified whether the name and address on the birth certificate matched with the occupant of the dwelling.

Data collection and analysis

Teams of phlebotomists and survey interviewers were trained regarding sample collection and survey response. During a scheduled visit to the home, the phlebotomist explained the study, obtained informed consent and drew a blood sample of the child. The survey interviewer conducted a maternal questionnaire and a visual assessment of the home.

Venipuncture samples were obtained on 60 percent of study children, and capillary samples were obtained for the remainder. Approximately 25 mothers indicated previous lead testing for their child. The interviewer assessment, maternal survey and release of medical information forms were completed and lead levels were obtained from the pediatrician.

Blood analysis was performed by a private certified lab using atomic absorption spectrophotometry, with a detection limit of 1 microgram per deciliter. Results were reported to the Mahoning County Childhood Lead Poisoning Prevention Program and personal pediatricians for appropriate follow-up.

Eligibility and Representativeness

Only 36 percent of birth certificate identified children were eligible to participate in the study. Results are shown in Table 1. Based upon information on mail delivery from postal carriers, "not known" respondents were classified as not eligible to participate in the study. As suggested

by the comparison of several study variables, such as year of structure, maternal age, years of education, birthweight in grams, and proportion white, such a procedure seemed reasonable. Average maternal years of completed school for the not eligible mothers, 12.2 years, was similar to the average education level of the "not known" mothers, 12.4 years. Eligible household mothers had completed an average of 13.4 years of education.

Response rate among eligible caregivers was almost 50 percent. To assure sample representativeness, mothers who refused to participate in the study were compared to mothers participating in the study. See Table 2. Maternal educational level and age for respondents and nonrespondants were similar. Although mothers with more recent homes were slightly more likely to refuse to participate in the study as were white mothers, no substantive differences between the groups were detected. Average year of dwelling construction for mothers refusing study participation was 1955 and average year of structure for mothers entering the study was 1949. Over 90 percent of nonrespondents were white, compared to 86 percent of study participants.

Variables and data analysis

Geometric or arithmetic means were calculated and compared to NHANES III data.[23,24] Variables included in the analysis were blood lead levels in micrograms per deciliter, a rating by the occupant of the dwelling as "excellent", "good", "fair" or "poor" (coded one through four, with four representing "poor" housing) and ethnicity (dummy coded white and nonwhite with nonwhite equal to 1). Actual year of dwelling construction was used in the regression analysis. Samples below the limit of detection were assigned the value of one-half of the detection limit. Because lead levels were not normally distributed, a data transformation, the base ten logarithm, was applied to the variable before predictive regression analysis.

Findings

Distribution of blood lead

Geometric mean blood levels for children in Mahoning County were similar to means reported for NHANES III study children. See Figure 1. For NHANES children aged 1 to 2, the mean blood lead level was 4.1 micrograms per deciliter and for children aged 3 to 5 the mean was 3.4 micrograms per deciliter. For Mahoning County children aged 1 to 3, the mean blood lead level was 3.3 micrograms per deciliter.

The distribution of blood lead levels in Mahoning County and in the NHANES study was similar. In Mahoning County, 29.6 percent of children 1 to 3 years old exhibited blood lead levels greater than 5 micrograms per deciliter, the median. In the NHANES study, 28.6 percent of the children exhibited similar blood lead levels. Because of confidence interval differences attributed to differences in study methodologies, no statistical tests were performed.

Bivariate analysis

As found in the NHANES, geometric mean blood lead levels for Mahoning County nonwhite children were higher than mean levels for white children. See Figure 3. The geometric mean blood lead level for non-hispanic, white children aged 1 to 3 was 3.0 micrograms per deciliter, and similar to the geometric mean for such children reported in the NHANES, 2.9 micrograms per deciliter. For non-hispanic blacks, the geometric mean blood lead for Mahoning County, 6.6 micrograms per deciliter, was twice as great as the mean lead level for white children.

Blood lead levels were highest for structures built prior to 1940 and were lowest for dwellings built after 1980. See Figure 4. Arithmetic mean blood lead was 6.82 micrograms per deciliter in pre 1940 dwellings and decreased monotonically for more recently built dwellings. Arithmetic blood lead mean for post 1980 dwellings was only 2.48 micrograms per deciliter.

Blood lead levels were highest for dwellings which mothers rated as "poor" and lowest for dwellings which mothers characterized as "excellent". See Figure 5. Blood lead levels were 2.83 micrograms per deciliter among dwellings rated as "excellent" and were 7.82 micrograms per deciliter for homes described as "poor".

Regression analysis

Blood lead levels were analyzed using multiple regression with forced entry of the variables race, maternal rating of dwelling, and year of structure. Thirty percent of the variability in blood lead for study children was explained by housing age, condition, and maternal ethnicity. See Table 3. No interaction terms among the variables were noted. Standardized and unstandardized regression coefficients and statistical tests for whether or not terms in the model differed from zero are shown in the table.

Spatial analysis

Program data from the Mahoning County lead program, study data and a map for Youngstown, Ohio generated using TIGER, a geographic information system available from the Census Bureau are shown in Figure 6. Three neighborhoods located north, east and south of the central business district of Youngstown

had a preponderance of exposed children. Census information suggested these neighborhoods are predominantly nonwhite with older, poorer quality housing stock.

Discussion

In Mahoning County, age and condition of housing stock was associated with childhood blood lead levels. Inner city neighborhoods were at greater risk of childhood plumbism. These neighborhood characteristics could be used to target screening activities. Mahoning County's model of blood lead predicted as much of the variability in blood lead as the NHANES model with far fewer variables.

In a recent report, 27 percent of the variability in blood lead was explained by age, gender, race, poverty, level of education, urban and region.[23] In Mahoning County, 30 percent of the variability in blood lead was predicted using year of structure, race, and rating the home as "excellent", "good", "fair" or "poor", thus achieving a more parsimonious predictive model. More research is needed to increase the predictive nature of the model.

Other communities could use this approach to target screening activities. Existing data to target and evaluate screening includes programmatic data, such as STELLAR, a case management and reporting software used by Ohio lead programs. TIGER files (aka GBF/ DIME files or a census tract street index) could also be used to target neighborhoods, as could other geographic or census information. Urban planning departments or local land use experts may also have information which would be useful for targeting screening efforts. However, such efforts should be guided by knowledge of the bias in screening data. Screening data may not reflect true population-based prevalence rates.

Mahoning County auditor data was particularly helpful in obtaining study data. Tax records kept by Mahoning County identified structures, their approximate age, renovations made to structures, the quality of neighborhoods in which a dwelling is located, recent market value of buildings, and many other variables which could be useful in targeting screening. Tax records represent an objective, independent and unobtrusive means of collecting data on housing units.

While some epidemiologists have attributed lead exposure to hand-to-mouth activity and pica of children, others have suggested that lead dust contributes to blood lead levels. The controversy over inhalation and ingestion of lead as biological pathways to exposure is not resolved by this data. Yet, the variables housing age and condition may represent a proxy variable which measures both pathways and is adequate for targeting.

To shed light on biological pathways the Cincinnati Study has investigated the relative contribution of dust and hand lead. Explaining how socioeconomic status directly effects blood lead levels remains problematic. Explanations for the racial disparity in blood levels and whether race differences have been exacerbated over time.

Changes in the relationship between housing age and condition and blood lead over time warrant further investigation. Monitoring such changes is necessary for targeting screening and perennial adjustments to include more or different neighborhoods. As a community's housing stock ages, pre 1978 dwellings which were not "lead free" but "lead safe" may represent a threat.

According the 1990 Census, 79 percent of the housing units in the Unites States were built prior to 1980.[25] Lead will continue to be a persistent poison. Children at greatest risk can be identified for targeted screening activities with data such as that used in Mahoning County.

ACKNOWLEDGMENT

Carol Pertowski, M.D., Lead Poisoning Prevention Branch, provided critique of this effort. Views expressed are those of the author. Funding was provided by the CDC through a grant to the Ohio Department of Health, Child and Maternal Health Division. Melissa Himes at Western Reserve Care System provided editorial assistance.

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ELIGIBILITY

Table 1

	NOT ELIGIBLE	ELIGIBLE	NOT KNOWN
YEAR HOME BUILT	1939 ± 104	1952 ± 26	1940 ± 26
MATERNAL AGE, years	24.4 ± 5.9	28.9 ± 5.8	25.6 ± 6.5
EDUCATION (Years Completed)	12.2 ± 2.1	13.4 ± 2.1	12.4 ± 1.9
BIRTHWEIGHT, grams	3206 ± 670	3367 ± 580	3288 ± 570
% WHITE	55.5 %	88.1 %	66.9 %

NOT ELIGIBLE: EXPIRED N=23, MOVED N=1036, OTHER N=3
ELIGIBLE: REFUSED N=441, COMPLETED N=421 (36 % OF BIRTHS)
NO CONTACT: IMPLIED REFUSED N=477, DISCONNECTED N=2, WRONG # N=13

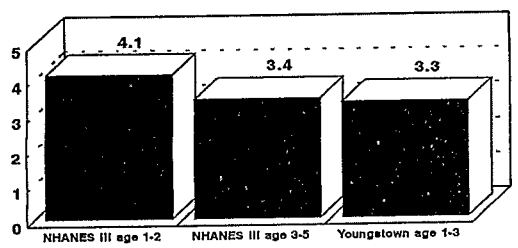
RESPONSE BIAS

Table 2

	OVERALL	COMPLETED	REFUSED	STATISTICAL TEST	P VALUE
YEAR HOME BUILT	1952 ± 26	1949 ± 26	1955 ± 26	F=11.216	0.001
MATERNAL AGE, years	28.9 ± 5.8	28.9 ± 5.5	28.9 ± 6.1	F=0.166	0.657
EDUCATION (Years Completed)	13.4 ± 2.1	13.4 ± 2.1	13.5 ± 2.1	F=0.442	0.506
BIRTHWEIGHT, grams	3367 ± 580	3368 ± 576	3376 ± 586	F=0.234	0.629
% WHITE	88.1 %	85.9 %	90.2 %	chi2=3.607	0.051

REFUSED N=441; COMPLETED N=421; RESPONSE RATE 48.8 %
OF THOSE ELIGIBLE: 36 % OF BIRTHS

Geometric Mean Blood Lead microgram/dL



ages 1-2 95% CI 3.7-4.5
ages 3-5 95% CI 3.0-3.8
Figure 1

Distribution of Blood Lead

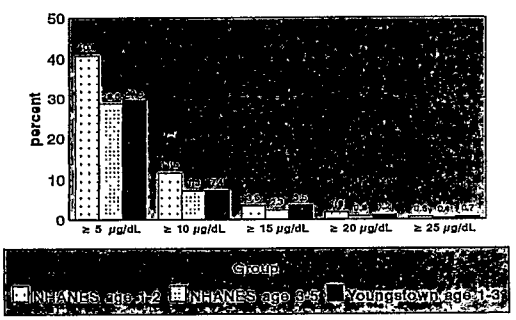
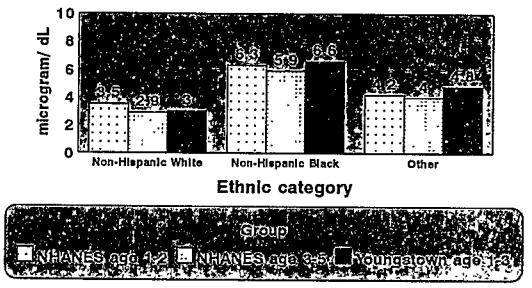


Figure 2

Geometric Mean Blood Lead By Ethnicity



White n=348, Black n=47, Other n=8
Figure 3

Blood Lead Levels by Housing Age Arithmetic Mean

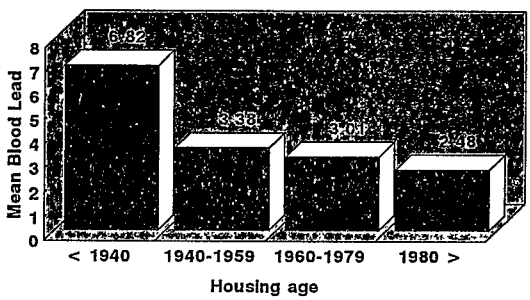


Figure 4

Blood Lead Levels by Maternal Rating of Home Arithmetic Mean

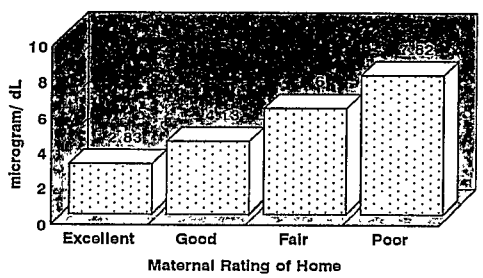


Figure 5

Linear Regression Analysis log 10 blood lead level, Youngstown, Ohio

Table 3

Variable	Unstandardized Coefficient	Standardized Coefficient β	student's t test	p value
Year	-0.0038	-0.3409	-7.153	<0.0001
Race	0.2157	0.2568	5.766	<0.0001
Home	0.0563	0.1400	3.034	0.0026
Constant	7.8815		7.415	<0.0001

Model Multiple R=0.553, R2=0.306, Adjusted R2=0.300
Model F 56.93, p < 0.0001

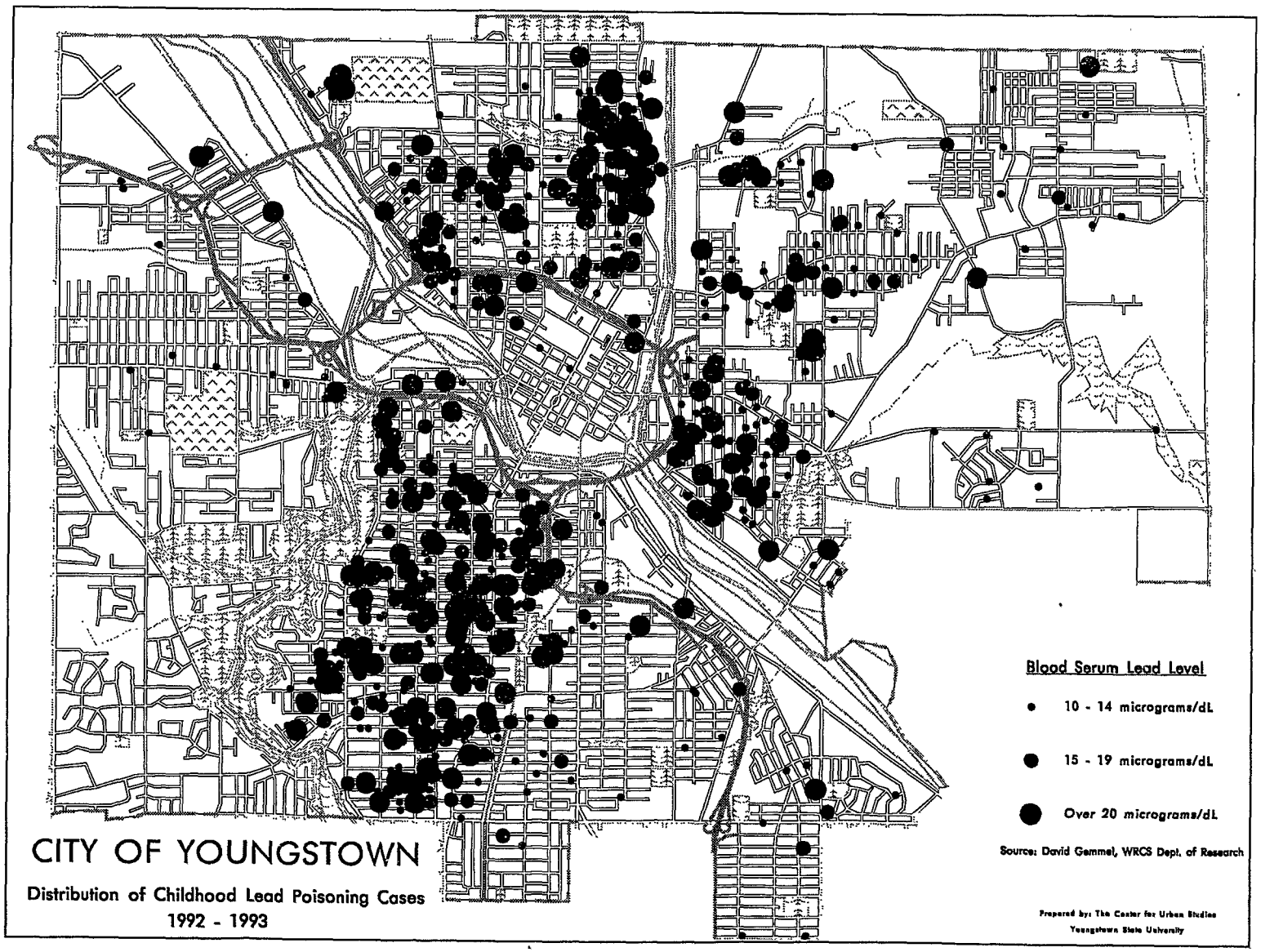

CITY OF YOUNGSTOWN
Distribution of Childhood Lead Poisoning Cases
1992 - 1993
Blood Serum Lead Level
10 - 14 micrograms/dL
15 - 19 micrograms/dL
Over 20 micrograms/dL
Source: David Gemmel, WRCS Dept. of Research
Prepared by: The Center for Urban Studies
Youngstown State University

Figure 6

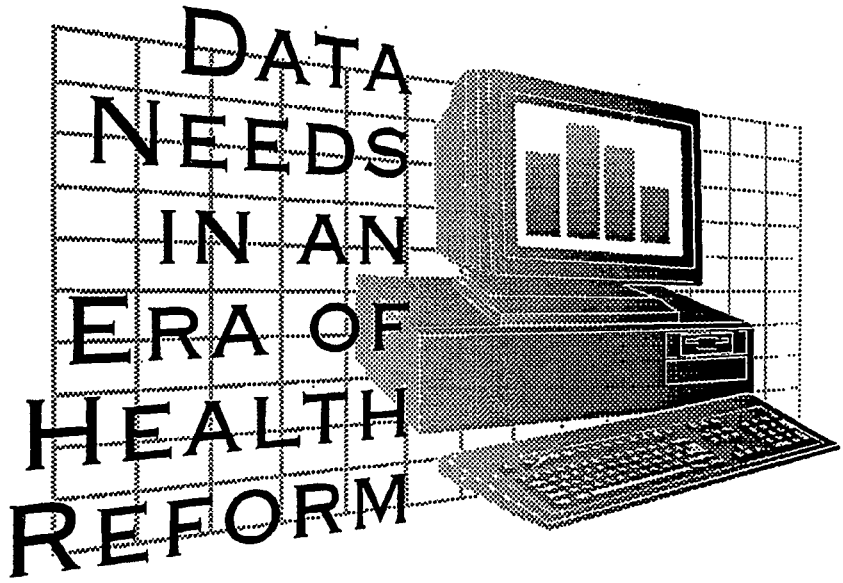
THE EFFECTS OF LIQUOR STORES

Thomas A. LaVeist
Johns Hopkins University School of Hygiene and Public Health

Paper not available for publication.

Session M

Children and Families



IMPLICATIONS OF ALTERNATIVE DEFINITIONS OF DISABILITY IN CHILDREN

Lauren E. Westbrook, Albert Einstein College of Medicine, Bronx, NY
Ellen J. Silver and Ruth E.K. Stein

INTRODUCTION

Data on children with disabilities are a priority right now for research, policy and programmatic purposes. Significant budget cuts to Medicaid, widespread implementation of managed care programs and other changes in the health care system have intensified the need to plan for services and benefits to children with chronic and disabling conditions.

Among the key issues that need to be addressed is how to determine eligibility for research, programs and services. Therefore, how disability should be defined for children is receiving a great deal of attention. Checklists of disease entities or symptoms to identify children are no longer consistent with the public policy movement. Rather, there has been a conceptual shift toward a more noncategorical approach (Pless & Pinkerton, 1975; Stein & Jessop, 1982). The noncategorical approach to identifying children with chronic conditions and disabilities applies generic criteria by examining the consequences of diverse health conditions (Stein et al., 1993).

There is no universally accepted definition of disability. Inconsistencies in how disability is defined make interpretation of data extremely difficult. We need to understand the implications of using different definitions for children with disabilities before data can be appropriately applied to policy and funding decisions.

As part of a larger effort to begin to elucidate the conceptual, methodological and definitional issues around disability, the Office of the Assistant Secretary for Planning and Evaluation has funded several projects to conduct secondary analyses of existing disability data. The data presented here are from one of these projects.

The purpose of our study is to examine the consequences and health policy implications of using different components of a noncategorically-based definition of disability developed by our research team to identify children in three existing data sets. This study is ongoing and we have not yet completed our analysis, but do have some preliminary results. First, the conceptual definition we used and the tool we developed to operationalize the definition will be described. Second, the data sets utilized for this analysis will be detailed. Third, our findings to date will be presented and our future analysis plans briefly outlined. Finally, we will offer several conclusions based on these preliminary results.

A NONCATEGORICAL QUESTIONNAIRE

In an earlier study, also headed by Dr. Ruth Stein, we developed a noncategorical questionnaire that reflects the consequences and impairments associated with chronic and disabling conditions in children under 18 years of age (Stein et al., 1993). The questionnaire taps three conceptual domains: functional limitations, service use beyond routine and reliance on compensatory mechanisms or assistance. These domains represent what we and a national advisory panel believe to be essential components to a comprehensive definition of disability in children that relies on noncategorical criteria. Each of these definitional components can be explained as follows.

Functional limitations are conceptualized as limitation of function, activities or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional and social growth and development. We operationalized functional limitations as being limited in play with other children; being restricted in activities; having difficulty feeding, dressing, washing or toileting; and having difficulty hearing, seeing or communicating.

Service use beyond routine care is conceptualized as the use of or need for medical care or related services, psychological services or educational services over and above the usual for the child's age, or use of or the need for special ongoing treatments, interventions or accommodations at home or in school. This domain reflects current service use as well as expressed needs for services that are not presently being met. We operationalized service use beyond routine care as hospitalizations, doctor visits, nursing care or treatment, physical or speech therapy, psychological services and special arrangements at school (for example, classroom or schedule modifications), special instruction or other educational services.

Reliance on compensatory mechanisms or assistance is conceptualized as dependency on an accommodating mechanism to compensate for or minimize limitation of function, activities or social role. Reliance on compensatory mechanisms or assistance was operationalized as

medication use, special diet and use of special equipment such as assistive devices, medical technology or personal assistance.

Functional limitations and utilization of medical and other related services typically are used in measures to identify and describe children with disabilities. The concept of "compensated" function with accommodations, however, is relatively new (Verbrugge, 1990) and has not before been applied to children. When abilities are maximized and symptoms are successfully reduced, many children who have disabilities will be functionally indistinguishable from healthy peers. But in order for successful compensation to occur, other consequences are necessarily imposed on these children. These compensatory consequences are what we are tapping in this domain. For example, the child with epilepsy whose seizures are controlled with medication would be identified with the item on medication use. The child with phenylketonuria who can live a normal life as long as a special diet is rigorously maintained would be identified with the item on special diet. In both instances, absence of treatment would be expected to produce functional impairments.

The questionnaire we developed, called the Questionnaire for Identifying Children with Chronic Conditions (QuICCC), identifies children who are currently experiencing consequences in any of the three domains just described: functional limitations, service use beyond routine and reliance on compensatory mechanisms or assistance. The QuICCC was originally designed to be used as a household survey. The respondent is usually the parent or caregiver who is the most knowledgeable about the health of the children living in the household. Because the age range is so broad (from birth to age 18) some of the questions are age specific.

The QuICCC consists of 39 items. The items are generally structured in three parts, as shown by the example provided in Table 1. A child is identified as having a chronic or disabling condition only if affirmative responses are given to all parts of a question sequence. Table 1 shows the item on medication use which reflects the domain of reliance on compensatory accommodations. The respondent is first asked if any of the children take medicine or drugs prescribed by a doctor other than regular vitamins. If the respondent answers "No" or "Don't Know", the interviewer skips to the next question. If the respondent answers "Yes", the interviewer asks if this is because of a medical, behavioral or other health condition that the child still has? If the answer is "No" or "Don't Know", the interviewer skips to the next question. If the answer is "Yes", the interviewer asks the respondent if this condition has been going on, or is expected to go on, for at least one year. Only if the respondent answers "Yes" to this and each proceeding part of the question is the child (or children) identified.

TABLE 1. SAMPLE ITEM FROM THE QUICCC

1a. Do any of the children [in the household] take medicine or drugs prescribed by a doctor other than regular vitamins?
1 ( ) Yes
2 ( ) No
3 ( ) Don't Know

b. Is this because of a medical, behavioral or other health condition that the child still has?
1 ( ) Yes
2 ( ) No
3 ( ) Don't Know

c. Has this condition been going on or is it expected to go on for at least one year?
1 ( ) Yes
2 ( ) No
3 ( ) Don't Know

An additional question at the end of each item that asks for the name of the condition is optional with the QuICCC. We included this query in our field tests for additional information, but it is neither essential to our definition, nor does it affect the QuICCC's ability to identify children.

RESEARCH QUESTIONS

The 39 item sets of the QuICCC were divided to reflect each of the three components of our noncategorical definition so that we could compare the consequences and health policy implications of using the individual components separately.

The analyses that follow address two specific research questions. First, what proportions of children are identified as disabled using different components of our noncategorical definition? Second, are children with different diagnoses and conditions identified using different components of our definition?

SAMPLE CHARACTERISTICS AND METHODS

Data from the QuICCC are currently available from two different sample populations: the National Sample is a cross-sectional sample of 1388 children from a random-digit-dial telephone survey of households conducted across the United States, and the Inner-City

Sample is a cross=sectional sample of 1275 predominantly minority children from a random-digit=dial telephone survey of households in a Northeastern inner-city. Table 2 describes some of the characteristics of the samples.

TABLE 2. SAMPLE CHARACTERISTICS

	National	Inner-City
N		
children	1388	1275
households	712	657
Sex (%)		
male	50	50
female	50	50
Age (%)		
mean (yrs)	8.2	7.6
0-5 years	34	41
6-10 years	30	27
11-17 years	36	32
Race/Ethnicity (%)		
white	80	14*
non-white	20	86
Education (%)		
< high school	11	29*
h.s. grad	38	29
> high school	51	42
Income (%)		
< $15,000	17	38*
> $15,000	83	62

* p <.001

RESULTS

The proportions of children identified by each of the three components of the definition are shown in the following figures. Figure 1 shows that in the National Sample, 258 of the 1388 children sampled or 19% were identified as disabled using the QuICCC. Slightly less than half (44%) met criteria in only one component of the definition. More than one-third (36%) met two of the three definition components and 20% were identified by items in all three components.

We wanted to examine more closely those children who were identified by only one component of the definition. Figure 1 also shows a further breakdown of this group. We found that 30% were identified by reliance on compensatory mechanisms or assistance, 47% by the service use component and 23% were identified as having functional limitations. The majority of children were identified by service use. However, one also can see that if we had limited our definition to service use as we operationalized it, or to any other single component for that matter, a significant proportion of children would have been mis-classified as healthy.

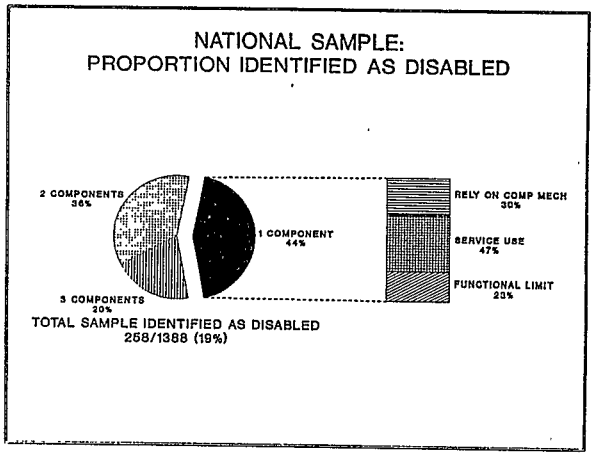


Figure 1. Proportion Identified as Disabled in National Sample

We repeated this analysis in the Inner-City Sample and found quite similar results. Figure 2 shows that overall, 246 out of the total sample of 1275 children (19%) were identified as disabled by at least one component of the Child Health Screen. This is exactly the same proportion of children as identified in the National Sample. Slightly more than half of these children (52%) met the criteria for only one component, 32% met two components of the definition and 16% met all three components.

Figure 2 also depicts the breakdown of children identified by only one component of the definition. Twenty-two percent were identified as relying on a compensatory accommodation, 48% as using or needing services beyond what is expected and 30% were identified as having functional limitations. Again, it is apparent that if any individual component of our definition had been used alone to identify disabled children, a substantial proportion of children would have been mis-classified as healthy.

In the next analysis, we examined whether children identified by different components of the definition would have different diagnoses and conditions. This information was obtained during field testing from the optional query described earlier. Respondents were asked to name the condition that caused the particular problem for the child.

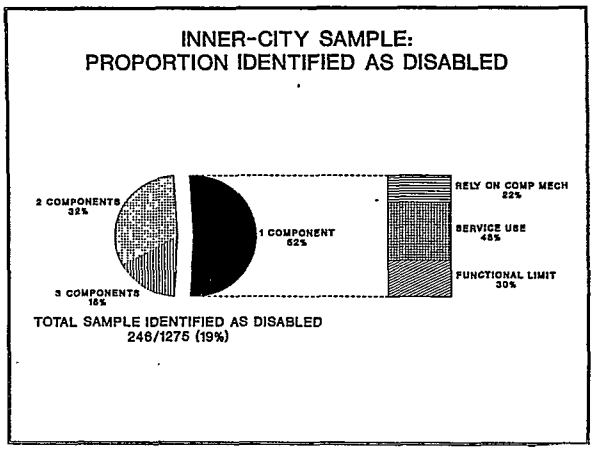


Figure 2. Proportion Identified as Disabled in Inner-City Sample

Note that we were not always able to get this information. Some respondents gave descriptions rather than "diagnoses" or said they simply did not know or could not remember the name of the health condition. This underlines one of the advantages of the QuICCC: children can be identified independent of the respondent's ability to name the condition.

Since there were no apparent differences in the types of conditions children had in the National and Inner-City Samples, we combined the two data sets for this analysis. Children who were identified only by functional limitations had conditions such as hearing impairments and deafness, visual impairments and blindness, diabetes, asthma, and epilepsy. Children identified only by service use or need beyond that expected had conditions such as behavioral and emotional disorders, multiple sclerosis, sickle cell anemia, asthma and epilepsy. Children identified only by their reliance on compensatory accommodations had conditions that included heart conditions, high cholesterol, hypertension, sickle cell anemia, asthma and epilepsy.

There is a considerable degree of overlap in the types of conditions found for children identified by the three components of our noncategorical definition of disability. Children with severe conditions are included in each. For example, children with asthma and epilepsy were reported to have a wide range of different consequences for the same condition. Some children were restricted in their activities or had difficulty performing tasks of daily living. Others were hospitalized, had frequent medical visits or needed nursing care or special school services. And still other children with the same condition were able to compensate and did not suffer from functional limitations or increased use or need of services, but did require medication, maintenance of special diets or assistive devices.

Children identified by all three components of our definition of disability tended to have more pervasive conditions such as Down syndrome and other forms of mental retardation, cerebral palsy, autism, deafness, spina bifida, and a variety of birth defects. These children also tended to have multiple conditions such as heart and kidney conditions, asthma and epilepsy.

FUTURE PLANS

Future analysis plans include further exploration of the characteristics of children identified by different components of our noncategorical definition of disability. We will describe demographic characteristics including age distributions and gender, socioeconomic status, impact on the family, federal program eligibility and out-of-pocket expenses. Second, other data sets will become available for analysis in the near future. For example, the QuICCC is currently part of a statewide, cross-sectional household survey of children in the state of Arizona, including a sample from the Native American population. We will repeat the same analyses in this data set. Finally, we plan to combine all three data sets together to assess whether there are racial and ethnic differences in the prevalence of disability as we have defined it, both overall, and by each of the three definitional components.

CONCLUSION

This paper reports preliminary results from an ongoing project designed to examine the policy implications of using alternative functional definitions of disability to identify children for research, policy or programmatic purposes. As this study progresses, we will consult with child health policy experts to help us draw out the policy implications of our data. At this time, we have two concluding remarks.

First, in using the definition of disability that we developed, we found that a significant proportion of disabled children would have been misidentified as healthy if any one component of our definition were omitted. This finding can only be interpreted with respect to our particular operationalization of disability as reflected in the QuICCC. But it does raise a larger issue. Obviously, for appropriate fiscal planning, we do not want to underestimate the number of children with chronic and disabling conditions. Who will be classified as

"disabled" and who will not is completely dependent on how we define disability. For different purposes, different definitional approaches and criteria will need to be developed. A comprehensive definition of disability for children that covers all concepts relevant to its application should help avoid some of the pitfalls inherent in underestimating prevalence.

Second, children identified with reliance on compensatory mechanisms or assistance may be a strategic group to examine from a disability policy perspective. Recent legislation relating to the American's with Disabilities Act of 1990 mandates a broader perspective with regard to the disabled community by addressing issues relevant to people who have ongoing health conditions with consequences, including those not directly experiencing disability in the classic sense. We see the dimension of reliance on compensatory accommodation as a critical component to our definition of disability, and we believe it may have enormous implications for planning and funding decisions for children with disabilities.

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YOUTH WITH RUNAWAY EXPERIENCES IN THE HOUSEHOLD POPULATION

Chris Ringwalt, Research Triangle Institute

The purpose of my talk today is to present prevalence estimates of the number of youth in the household population with runaway experiences, as well as correlates of runaway experiences. Runaway adolescents are particularly vulnerable for such negative physical, psychological, and social health outcomes as substance use, suicide, sexual exploitation, and physical violence. Runaway youth face a multitude of dangers while away from home. That they need a wide variety of services is unquestionable, as are the high costs they will impose on society if their needs are not met effectively. It is also clear that their needs are not now being met adequately, and that the limited services they currently receive are in danger of eroding further. Hence, they also meet the other criterion of vulnerable populations mentioned in Dr. Richard Brown's presentation this morning.

Our objectives in this study are twofold:

- to estimate the number of youth in the household population who reported previous runaway experiences, as well as the number of runaway youth who may have also had homeless episodes, and
- to estimate drug use and other at-risk behaviors among youth with previous runaway experiences and compare these estimates to those of youth who reported no runaway experiences.

Only one cost-effective methodology suggested itself as a means to meet these objectives: to add questions concerning runaway experiences and homeless episodes to a national household-based survey of youth that included questions about drug use and other risky behaviors. As a further requirement, the survey needed to be of sufficient size that a reasonable number of youth would respond positively to questions about relatively rare runaway experiences and homeless episodes. As we were aware, too small a sample would prevent meaningful comparisons to youth without these experiences.

We were thus fortunate to be able to add questions concerning these epxeriences to the Youth Risk Behavior Supplement (YRBS), which was conducted as a follow-up to the National Health Interview Survey (NHIS). For the YRBS, a sample of youth aged 12 to 21 was drawn from the 49,401 families interviewed for the NHIS. Within each family selected, one youth attending school and up to two youth not in school were selected. Of the 13,789 youth sampled, interviews were completed with 10,645 adolescents, yielding a final response rate of 77.2%. Of these, we analyzed the responses of all 6,497 youth aged 12 to 17, choosing as the upper bound the age beyond which youth are no longer considered runaway.

Data collection for the YRBS covered a 12-month period from April 1992 through March 1993. Surveys were conducted by means of taped interviews delivered by audiocassettes. Youth listened to the interviews and recorded their answers on forms that included response options but not the questions themselves. Upon completion of the interview, youth returned the answer sheets in sealed envelopes to interviewers. This procedure assisted youth of marginal literacy and protected the privacy of all adolescents' answers from potentially prying eyes of family members.

The questions we added to the YRBS may be found in Exhibit 1. The question we asked concerning running away is quite conventional and has been used elsewhere (e.g., Finkelhor, Hotaling, & Sedlak, 1990). However, there is much less consensus in the research community concerning how to operationalize homelessness for adolescent populations. We asked youth about key locations where youth might have spent the night (or the "where" of homelessness). However, for reasons of space, we were constrained from tapping the temporal dimension of the experiences of these youth (or the "how long" of homelessness). Therefore, these questions should be considered indicators of homelessness.

Exhibit 1
Questions Concerning Runaway Experiences and Homeless Episodes

Runaway Experience

During the past 12 months, have you stayed out overnight without permission?

Homeless Episodes

During the past 12 months, did you spend at least one night in:

1 a youth or adult shelter?

2 a public place, like a train or bus station, a restaurant, or an office building?

3 an abandoned building?

4 a car, truck, or van?

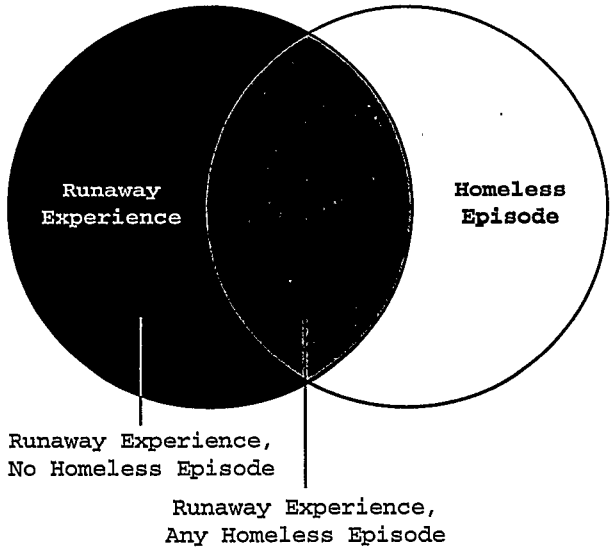
5 a park, on the street, under a bridge or overhang, or on a roof top?

6 did you go home with someone you did not know because you needed a place to stay?

7 the subway, or other public place underground?

We now turn to our findings as they relate to the objectives we set forth earlier. We have made several key comparisons, which are depicted in Exhibit 2. To understand this exhibit, it is important to recognize that youth could have reported a runaway experience, or any one of the homeless episodes about which they were asked, or both. Hence, the two circles intersect but do not overlap. In our findings, we compare youth who indicated they had run away to those who reported neither a runaway experience nor a homeless episode. We also compare to this latter group runaway youth who reported at least one homeless episode (the gray area in the exhibit) and runaway youth who reported no homeless episodes (the black area). We expected that youth with both runaway experiences and homeless episodes would be more likely to demonstrate risky behaviors than would youth with runaway experiences but no homeless episodes. Not included in our comparisons are youth who reported at least one homeless episode, but no runaway experiences. (Note that we have no way to determine whether youth who reported a homeless episode did so while away from home without permission. That is, their runaway experiences and homeless episodes could have occurred contemporaneously or at different times during the 12-month reference period.)

Exhibit 2
Definitions of Runaway Experiences



In Exhibit 3, we display estimates of the number of youth nationwide in the household population who reported runaway experiences in the previous 12 months, and among those the number who also reported any possible homeless episodes within the same reference period. Note that almost one out of seven adolescents reported at least one runaway experience, and that of those almost one out of five also reported a homeless episode. Although these estimates are higher than those previously reported for the adolescent population (Finkelhor et al., 1990; Opinion Research Coporation, 1976), they are commensurate in magnitude with those of a recently published study concerning homelessness among adults (Link, Susser, Stueve, Phelan, Moore, & Struening, 1994).

Exhibit 3
Percentage and Estimated Number of Youth Aged 12 to 17 Reporting Runaway Experiences
(*N*=6,497)

Runaway Experiences	Unweighted *N*	Weighted *N*	(SE)	%	(SE)
Runaway experience, no homeless episode	692	2,270,849	(123,263)	12.0	(0.56)
Runaway experience, any homeless episode	157	522,629	(49,894)	2.8	(0.24)
Any runaway experience	849	2,793,478	(141,751)	14.8	(0.61)

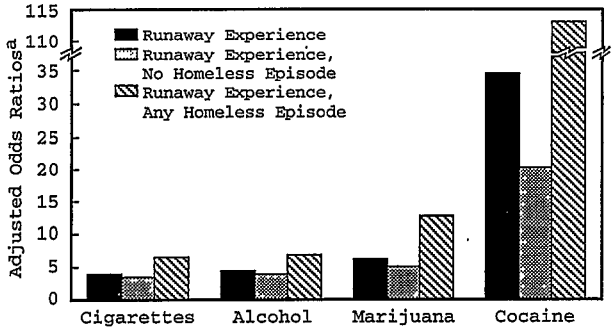
We then looked further at youth who reported a runaway experience and the location of each homeless episode in the previous 12 months and estimated the number of each. As Exhibit 4 indicates, the greatest number reported that they stayed outside (i.e., in a park, on the street, under a bridge, or on a rooftop) and that the least number reported staying in a subway or underground (questions 5 and 7 in Exhibit 1, respectively). These relative responses are about what we expected, given the ready availability of outside locations as opposed to the relatively small number of urban areas with subway systems. These responses thus suggest that the number of adolescents who answered questions capriciously was quite limited.

Exhibit 4
Estimated Numer of Youth Who Reported a Runaway Experience and Location of Each Homeless Episode
(*N*=6,497)

Locations	Unweighted *N*	Weighted *N*	SE
Outside	61	199,906	(30,829)
Public place	43	146,583	(24,734)
Youth or adult shelter	41	136,905	(23,616)
With a stranger	37	111,240	(19,935)
Abandoned building	34	104,540	(20,692)
Subway	6	22,295	(10,316)

We now turn to comparisons of risk behaviors among youth with runaway experiences to those without either runaway experiences or homeless episodes. Note in Exhibit 5 that that the vertical bars represent odds ratios for past 30-day substance use that have been adjusted for adolescents' age, gender, racial/ethnic background, familial poverty status, and the population density of the area in which they live (metropolitan statistical area [MSA] status). As you might expect, the tallest bars (i.e., the highest odds ratios) are youth who reported both runaway experiences and homeless episodes. The odds ratios associated with past 30-day cocaine use are particularly dramatic, but even those indicating elevated risk for the other substances examined (cigarettes, alcohol, and marijuana) are in the neighborhood of five times greater for youth with runaway experiences than for those without. The odds ratios associated with other risk behaviors about which we asked (including carrying guns, knives, and clubs in the past 30 days, physical fighting in the past 12 months, sexual intercourse in the past 3 months, and lifetime prevalence of sexually transmitted diseases [STDs]) were more modest, but all exceeded a factor of 3. Youth aged 14 to 17 reporting both runaway experiences and homeless episodes were 10 times as likely to report a lifetime STD as those with no runaway experiences.

Exhibit 5
Past 30-Day Substance Use Among Youth Aged 12 to 17 with Runaway Experiences
(*N*=6,497)



[a]Adjusted for age, gender, ethnicity, metropolitan statistical area status, and poverty and compared to no runaway experience.

These findings serve to illustrate the importance of administering risk behavior surveys to large, nationally representative samples of youth. Such samples are highly effective as a means to tap and estimate relatively rare behaviors. They are much more effective than school samples, which are subject to bias in that they do not include those who are often the most

likely to engage in the behaviors of interest (i.e., dropouts). Analyses of such survey data can demonstrate convincingly the increased risk of special populations of interest (e.g., runaway youth) of key risk behaviors and also suggest specific prevention efforts for this population (e.g., STD and cocaine prevention). Such surveys can also serve to track changes in the prevalence of special populations over time and variations in the risk behaviors in which they engage.

There is simply no other meaningful, cost-effective way to count the number of youth with runaway experiences and homeless episodes other than by a survey of this nature. It is highly unlikely that a nationally representative sample of street youth will ever be enumerated because of the excessive costs involved. It is also arguable that to devote scarce public resources to counting, as opposed to serving, runaway and homeless youth would be unethical. For these reasons, future administrations of risk behavior surveys such as the one reported here deserve our unequivocal support.

Acknowledgments

This paper was written by Chris Ringwalt, Research Triangle Institute, Research Triangle Park, North Carolina, under grant no. DA-08849 from the National Institute on Drug Ause.

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IDENTIFICATION AND TREATMENT OF PEDIATRIC ASTHMA PATIENTS ACROSS SITES OF AN INTEGRATED SERVICE DELIVERY AREA

Jeff Eickholt, Mayo Clinic, Mayo Foundation
Charles Darby, Greg Angstman, Lynn Kelley, Steve Hagedorn

Introduction

In this era of health care reform, it has become very important to deliver the highest quality of care to patients and at the same time stabilize or reduce the costs associated with that care. In this paper, we define pediatric asthma and describe its various medical, social, and financial effects on children and their families. We then outline currently recommended treatment regimens for children with asthma. Finally, we will describe a study that we completed to evaluate the patterns of asthma medicine prescriptions at three primary care sites within our institution. The goal of this study was to support the implementation of a clinical guideline intended to improve the quality of care given to pediatric asthma patients at our institution. In improving the care, we hope to improve the health of children with asthma and also lessen the financial burden by lowering the number of emergency room visits and hospitalizations related to asthma.

Asthma is a lung disease that is characterized by airway obstruction that is reversible in most patients, either spontaneously or with treatment. Other characteristics of asthma include airway inflammation, decreased airway capacity, and increased airway responsiveness to a number of stimuli, including exercise, cold air, smoke, dust, and other allergens. Clinical manifestations associated with asthma include coughing, wheezing, tightness of chest, and difficulty in breathing. Signs and symptoms vary greatly between individuals, depending on the severity of asthma.

The exact mechanisms and causes of asthma are still not completely understood and there is currently no known cure for this disease. Recent research, however, has identified medication regimens and treatment protocols that allow physicians to better manage children with asthma. A 1991 expert panel report[1] on this condition outlined guidelines for the management of asthmatic patients using these medications and other methods.

Affects of Asthma

Asthma is the leading chronic disease among children[4] affecting 4 to 6 % of children in the United States.[2,3] Prevalence rates are highest among males, blacks, and children of households earning less than a poverty level income.[2] The prevalence rate, for undetermined reasons, has risen 30 to 40 % during the 1980's.[2,5] Despite decades of extensive research that has identified methods of better managing asthma patients, the average asthma-related mortality rate for children aged 5-14 years increased 10 percent per year from 1980 to 1987.[6]

The quality of the lives of children can be greatly impacted by asthma. It has been estimated that as many as 30% of children with asthma have limited activity and that children with asthma miss on average twice as many school days as non-asthmatic children.[7]

Asthma has a great physical and psychological effect on children and also a great financial impact upon their families. Asthma is a chronic condition that requires regular visits to physicians and regular use of medications. Some exacerbations of asthma may require emergency room visits and hospitalizations. It has been estimated that children have nearly 13 million contacts with health care providers each year directly attributable to asthma.[2] In addition, there are 150,000 to 200,000 asthma-related hospitalizations each year among children.[2,4]

Severity

The severity of asthma varies greatly from child to child and is a key factor when considering therapy. Mild asthma is characterized by exacerbations that are infrequent and usually short in duration. These exacerbations usually resolve spontaneously or with medication that can be administered by the patient, or caretaker, without a physician visit. Between exacerbations, mild asthmatics show few signs or symptoms and tolerate moderate exercise well, but may become symptomatic with vigorous exercise.

Children with moderate asthma have more serious and frequent exacerbations. These episodes may occur more than twice per week and the symptoms may last for several days. Between exacerbations, these children may continue to have some symptoms, including coughing and wheezing. The moderate asthmatic also generally experiences diminished exercise tolerance.

Severe asthma is characterized by an almost continuous coughing and wheezing. The severe asthmatic can experience frequent, sudden, and severe exacerbations and will often need urgent medical care to bring exacerbations under control. The severe asthmatic has very poor exercise tolerance.

Recommended treatment

In 1991, an expert panel[1] published guidelines for the diagnosis and management of asthma. This report specifically addressed the treatment and management of children with asthma. It describes the following goals of therapy: (1) maintain normal activity levels;

(2) maintain "normal" pulmonary function; (3) prevent chronic and troublesome symptoms; (4) prevent recurrent exacerbations of asthma; (5) avoid adverse effects of asthma medications.

The key components of asthma management include education, avoidance of triggers, monitoring, and pharmacologic therapy. For this project we restricted our study to pharmacological asthma management. In keeping with the panel report, which details various individual treatment regimens, it is important to reiterate that no single treatment regimen can or should be prescribed for all children with asthma. Regimens are, rather, tailored to the individual after physician examination and evaluation, and treatment is based on asthma severity. Because severity levels may change over time, it is important that the physician evaluate and document the degree of severity regularly, and adjust treatment accordingly.

A child with mild asthma should generally receive a beta-2 agonist, to be used as needed to alleviate acute exacerbations. Beta-2 Agonists act by reducing airway obstruction.

Moderate asthmatics should receive beta-2 agonists to be used on a regular basis. In addition, they should receive one or more anti-inflammatory medications, such as cromolyn sodium or a corticosteroid. These medications should be used on a regular basis to prevent and reduce inflammation of the airways.

A child having severe asthma requires a more aggressive approach. It is recommended that these patients receive a beta-2 agonist to be used on a regular basis. In addition, corticosteroids and cromolyn sodium are also recommended. This class of patient may also need additional medications, such as theophylline, to control their asthma.

Methodology

The Mayo Clinic is made up of a number of different types of clinical care providers, including primary care sites, pediatrics, allergy specialty areas, urgent care centers, and affiliated hospitals. Children with pediatric asthma can be seen at any one of these sites or at combinations of the sites. In this study, we used patient billing data to identify children with a primary diagnosis of asthma who were seen in at least one of three primary care sites. These sites included family medicine, pediatrics, and our pediatric allergy center. We also identified patients seen in three of our acute care areas. These included an urgent care center, emergency room, and a hospital.

Our clinical nurse abstractors then reviewed the histories of these patients and recorded information pertinent to each asthma patient, including additional visits, prescribed medications, severity documentation, diagnostic tests, and other clinical detail for the four-month period from September 1993 through December 1993.

Results

During these four months, we identified 573 asthmatic children that were seen in at least one of the six sites mentioned above. These patients averaged 1.9 visits each for a total of 1,119 asthma-related visits to the six sites during this four month period. The children ranged in age from 3 months to 16 years (mean=7.5 years, S.D.=4.2) and 61% were males. Asthma severity was documented in fewer than ten percent of patient medical histories during the selected period.

We categorized the patients according to which of the three primary care sites they visited. Table 1 summarizes information about the patients by their primary care site. Sixty-nine percent of the patients were being seen exclusively at one of the three primary care sites. An additional 6% were seen in more than one of the sites. Twenty-five percent of the patients were seen only in an urgent care, emergency room, or hospital setting and had no visits to the three primary care sites during these four months.

We were primarily interested in medication prescription patterns at the three primary care sites, so we restricted our analysis to the 430 patients with one or more primary care visits. For each of these sites, including the group seen at multiple sites, we examined all primary care visits for each child and recorded which medications had been prescribed at any time during the study period. Ninety-four percent of the patients had some type of asthma medication prescribed during this time period. Of the patients with a medication prescribed, 87% could be grouped

Table 1: Patient Characteristics by Primary Care Site

Site	Number of Children (%)	Average Number of Visits	Average Age
Family Medicine	41 (7.2)	2.4	7.7
Pediatrics	118 (20.6)	2.5	6.4
Allergy	237 (41.4)	1.9	8.2
Multiple Primary Care Sites	34 (5.9)	5.3	5.2
No Primary Care*	143 (25.0)	1.4	7.8

*Patients seen only at urgent care site, emergency room, or hospital.

into five standard or recommended treatment regimens: Beta-2 agonist alone, Beta-2 agonist + oral steroid, Beta-2 agonist + inhaled steroid, Beta-2 agonist + cromolyn sodium, and Beta-2 agonist + cromolyn sodium + steroid in Figure 1. The other 13% included patients who did not receive a beta-2 agonist (6%), patients that received a xanthine (3%), and patients that received both oral and inhaled corticosteroids (4%).

Ninety-four percent of treated patients received a beta-2 agonist. However, the patients seen in family medicine and pediatrics received the beta-2 agonist without other medication more often than patients seen in the allergy site or in multiple sites. The patients seen in the allergy site and in multiple sites received corticosteroids and cromolyn sodium more often than patients seen in the other two sites.

In addition to medications, we also examined the number of emergency room visits and hospitalizations each child had after a primary care visit. Fifteen percent, thirteen percent, and twenty-nine percent of the family medicine, pediatrics, and the combination group patients, respectively, had an emergency room visit or hospitalization, while only seven percent of the allergy patients visited the emergency room or hospital.

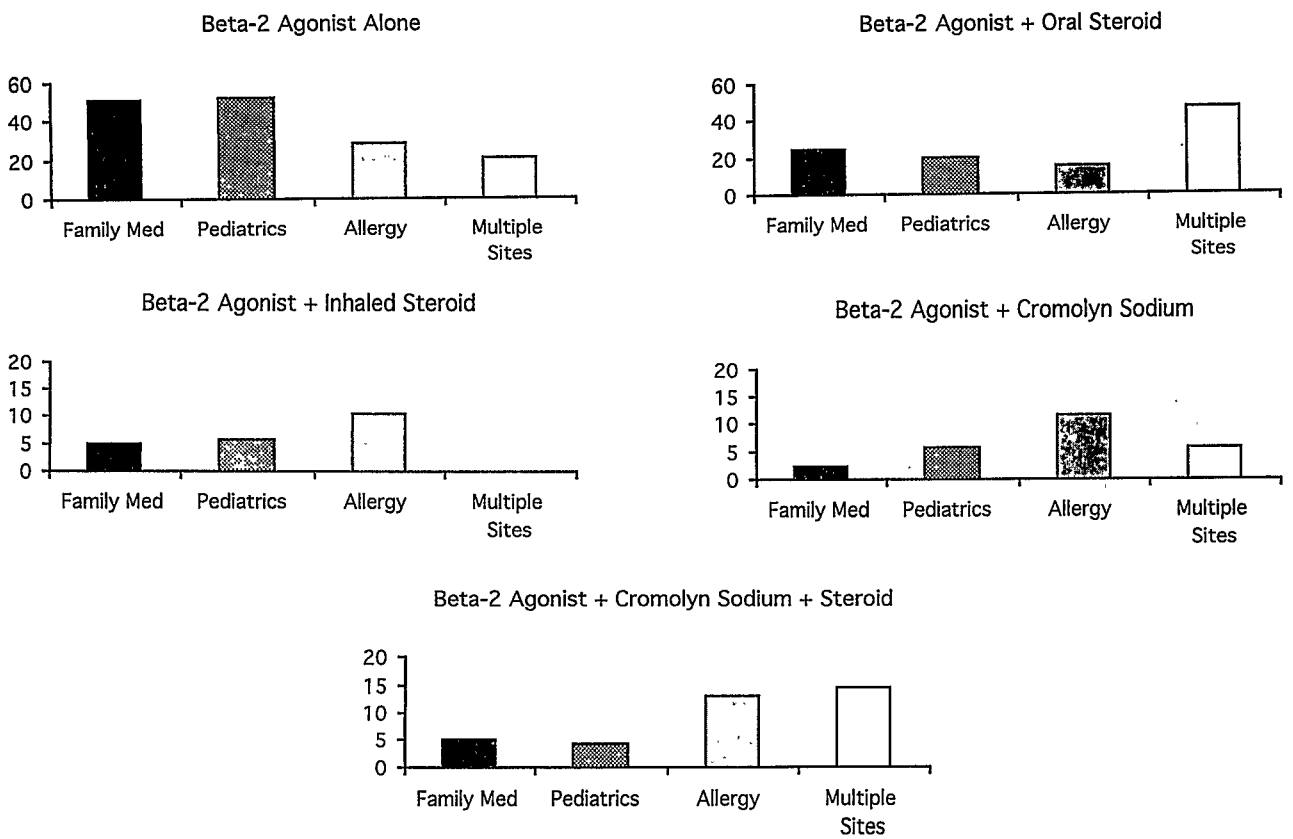
Limitations

There are limitations to our results. First, patients were only followed over a four month period, during which treatment may not have represented the overall treatment pattern. Also, we did not separate newly diagnosed patients from those with chronic asthma diagnoses, which may have skewed the overall picture of the pattern of medications prescribed. Finally, since asthma severity information was rarely documented, we were unable to correlate level of severity to medication use, or to directly compare asthma management across sites. Despite these limitations, however, our study revealed useful and interesting information, as described below.

Discussion

National guidelines advise that all children with asthma have a primary care provider to manage their condition. Twenty-five percent of the children that we studied had no asthma-related visits to the three primary care sites we examined. These patients may have a primary care provider outside of our system or may not have a primary care provider at all. Another 6% had

Figure 1: Proportion of patients that were prescribed each asthma medication regimen by primary care site



visits to multiple sites, suggesting that they have no main primary care provider to manage their asthma. A key component of the guideline implementation will be identifying children seen in acute care areas or in multiple primary care sites that have no primary care physician to manage their asthma. Attempts will then be made to refer these patients to a primary care provider.

The guideline also suggests that the severity of the asthma should be documented on a regular basis in order to properly manage the condition. There was very little documentation about the severity of asthma in this group of patients. Methods to improve this documentation will be included in the implementation of the guideline. Clearly indicating the severity of asthma should guide clinicians' decisions on which asthma medications to prescribe.

There were differences in the use of medications across the sites. We know that many of the more severe asthma cases will be followed by the asthma specialists in the pediatric allergy center. This would explain why a higher percentage of patients at this site were prescribed anti-inflammatory agents and corticosteroids. However, a greater percentage of children being seen at family medicine and pediatrics, which had similar treatment patterns, had visits to the emergency room or a hospital, suggesting that these sites are also seeing moderate and severe cases of asthma.

In considering the group of 34 patients who were seen at multiple sites, most were first seen in family medicine or pediatrics and were eventually seen by a specialist in the allergy center. These patients had the highest number of visits overall, the highest rate of treatment, and also had the highest rate of emergency room visits and hospitalizations. This suggests that many of these patients had severe asthma that may not have been in control. This makes it difficult to compare them to patients seen in only one site. In any case, the majority of these patients were referred to the pediatric allergy center, which is precisely the management advised by both national and institutional guidelines.

Conclusion

We have evaluated pediatric asthma patient site visit patterns and also the use of asthma medications at our institution. In doing so, we identified specific components of the proper management of asthma that need to be improved. We have also shown that the use of medications is not the same at every site. However, since we cannot control for severity, we cannot evaluate compliance with recommended guidelines or make comparisons between sites.

These results suggest that there exists substantial variation between the three primary care sites evaluated with respect to the nationally recommended guidelines for the management of children with asthma. We believe implementation of our clinical guideline at these sites will better meet the treatment needs of children with asthma. After implementation, these measures will be repeated on a regular basis to assess the effect the guideline has had on the quality of care given to asthmatic children.

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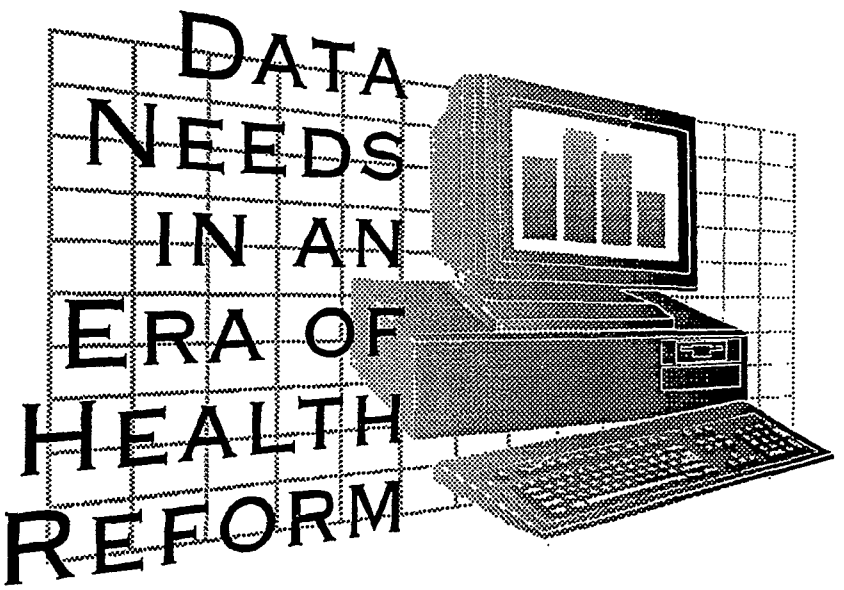
CHILDREN AND FAMILIES
Discussant

Matthew W. Stagner
Office of Assistant Secretary for Planning and Evaluation

Comments not available for publication.

Session N

The Chronically Ill or Disabled



ACCESS TO HEALTH CARE AMONG PERSONS WITH DISABILITIES: UNITED STATES

Frances M. Chevarley, Division of Health Interview Statistics, NCHS
Gerry Hendershot

INTRODUCTION

In this paper we analyzed data from the 1993 National Health Interview Survey (NHIS) and showed that work disability affects 1 in 8 adults 25-64 years of age in the United States. We also showed that in comparison to people without work disability, people with work disability are less likely to be in the labor force, more likely to be poor, as likely to have health insurance, less likely to have private health insurance, more likely to have a usual source of medical care, and less likely to receive needed and timely care.

Work in this area using earlier NHIS data has been done by Mitchell P. LaPlante[1] at the Institute for Health & Aging, University of California, San Francisco, CA, and Robert Griss[2,3] at the Center on Disability and Health, Washington, DC.

BACKGROUND

The National Health Interview Survey (NHIS) is an annual, nationally representative sample survey of the household population sponsored by the National Center for Health Statistics. Personal interviews are conducted in sample households by specially trained interviewers employed by the Census Bureau. The 1993 NHIS sample consisted of about 43,000 households containing about 110,000 persons[4]. The NHIS basic questionnaire contains comprehensive questions on health status and health care utilization. In addition to the yearly NHIS Core data, special studies are often done. In 1993, special studies were done on access to health care and health insurance, as well as other topics. Those topics were repeated in 1994 and 1995, years which also included a very detailed questionnaire on disability. The latest available data linking disability, health insurance, and access to care are the 1993 data used in this analysis. The first of the 1994 data with the more detailed information on disability is scheduled to be available Spring of 1996.

As defined by the World Health Organization, disability refers to the consequences of bodily impairments which limit the functional performance or activity of an individual[2]. Disability information is available yearly from the NHIS Core set of questions that are asked about limitation of activities, including work limitations, and their associated chronic conditions or impairments. A chronic condition is defined as a present condition occurring 3 months or more before the reference date of the interview or belonging to a group of conditions considered to be chronic.[4] An impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function within the body.[2]

All persons 18 years of age and older in the family are asked questions about whether they have any impairments or health problems that keep them from NOW working at a job or business, or limits the amount or kind of work they can do. If a work limitation is reported, AND it is associated with a chronic health condition or impairment, the person is considered to have a work disability. The categories of work disability that we used are: Unable to work; Limited in the amount or kind of work; and Not limited in the amount or kind of work. Included in the last group of Not work limited are those people who may have limitations that are not work limitations, and also people where it is unknown whether they have work limitations. We limited our analysis to persons 25-64 years of age to ensure the analysis of full-time labor force candidates. Persons younger than 25 and over than 65, respectively, are often not in the labor force because of school or retirement.

RESULTS

In 1993, according to Table 1 and Figure 1, 15.6 million people age 25-64 had work disabilities; they made up 12% of the population in that age group. A total of 56% of the "work disabled" or 8.8 million people were unable to work and 44% or 6.8 million were limited in the amount or kind of work they could do.

People with work disabilities are more likely to be poor. In 1993, only 16% of people with no work disability had incomes less than $20,000; where as 48%, or almost half of those unable to work had incomes less than $20,000. The percent of people who are limited in the amount or kind of work with incomes less than $20,000 is 29%, between the two other groups. About 47% of people with no "work disabilities" have incomes of $35,000 or greater, compared with 16% of people unable to work (Table 1).

One reason work disability is associated with low income, of course, is that persons with work disability are less likely to work or to work at well-paying jobs. Whereas 84 percent of persons without a work disability are in the labor force--either employed or seeking employment--only 78 percent of persons with a limitation in the kind or amount of work are in the labor force, and of those reported to be unable to work, only 18 percent are in the labor force (Table 1).

Because most persons receive health insurance coverage through their place of employment, it is not surprising that work disability is associated with health insurance coverage. Persons with a work disability are as likely to have health insurance, but the important difference is in the type of coverage: whereas 73 percent of persons without a disability are covered by a private insurance policy, only 38 percent of persons unable to work have private coverage; on the other hand, hardly any persons without a disability are covered by public or other health insurance coverage, but nearly two-fifths of those unable to work depend on these two categories (Table 1). Public HI coverage includes Medicaid and other public assistance; Other HI Coverage includes Medicare, Military Health care and health care from the Indian Health service. Persons unable to work are therefore much more likely to depend on these public programs for their medical care.

Health insurance coverage can affect access to health care through its affect on a person's having a usual source of sick care. A very large proportion of persons with health insurance coverage report that they have a usual place that they go when they are sick or need medical advice, and this is true regardless of the kind of insurance they have--private, public, or other--and regardless of their work

disability status (Figure 2). Among persons who have no health insurance coverage, a significantly smaller proportion have a usual source of care.

Among those with no health insurance coverage, however, work disability is associated with an increase in the probability of having a usual source of care. Among persons without a work disability, 58 percent of those without coverage had no usual source of care; but among those unable to work and no coverage, 77 percent had a usual source of care (Figure 2). This may be true because persons who are work disabled may have more need of a usual source of care.

We turn now to two more direct measures of access to care among persons with work disabilities: not getting care that was needed during the past year, and delaying medical care because of worry about the cost. Because health insurance and having a usual source of sick care affect access to care, we considered disability and access within four insurance and source categories: has health insurance and a usual source of sick care (HI w/ USC); has insurance but no usual source of care (HI w/o USC); has no insurance but has a usual source (No HI w/ USC); and has neither health insurance nor a usual source of care (No HI w/o USC).

Those categories in that order show a consistent and marked relationship to not getting needed medical care: those with health insurance coverage and a usual source of sick care were least likely not to get needed medical care, and those with neither insurance or usual source were most likely not to get needed care (Figure 3). The relative differences are very large: those in the least favored category are 6-12 times more likely not to get needed medical care.

Furthermore, disability is related to not getting needed care independently of insurance and usual source of care. Whether or not they had insurance or a usual source of care, persons with a work disability were more likely not to get needed medical care (Figure 3).

While many persons with work disability reported not getting needed medical care, many more reported delaying needed medical care for financial reasons. While both health insurance coverage and having a usual source of medical care are related to financially motivated delays in seeking care, health insurance is the more significant factor (Figure 4). Again, the effects are much greater among those with a work disability, whether moderate or severe: more than one-half of persons with a work disability and no health care coverage reported having delayed getting medical care for financial reasons during the past year.

DISCUSSION AND CONCLUSION

In conclusion, we showed that work disability affects 1 in 8 adults 25-64 years of age in the United States. People with work disability are less likely to be in the labor force, and more likely to be poor.

We found that people with work disabilities were as likely to have health insurance coverage as people not disabled but we found their type of coverage was different. People with work disabilities were less likely to have private insurance and more likely to depend on public programs such as Medicaid, Public Assistance and Medicare. A future public policy issue may be extending private insurance coverage to more people with disabilities. That policy issue was addressed partially in 1986 when legislation was enacted which made it possible for people to continue their private health insurance coverage after leaving a job by paying both the employer and employee contributions of the insurance premiums[2].

Besides health insurance coverage, we looked at 3 other measures of access to care: having a usual source of care; needing but not getting medical care; and delaying medical care because of cost. Although they are important indicators, these measures do not give the whole picture of adequate health care access. Additional information on quality and appropriateness of care are needed.

The 1993 NHIS does have other access to health care information that we have not presented. For instance there are several questions asking about the type of health professional that a person usually sees at the usual source of sick care and, if a doctor, whether or not the doctor is a specialist or general practitioner. There are also questions on consumer satisfaction at the place of usual care, such as waiting time for an appointment, waiting time to see the doctor when they had an appointment, satisfaction about getting the care they thought was needed, and whether the doctor was able to make referrals to other specialists.

Our analysis to date is preliminary and needs to be expanded. Besides this information from the 1993 NHIS, the Disability Supplement of 1994 and 1995 will have much more detailed disability information. There are also other government surveys that ask about health care. For instance, detailed cost of medical care is available from NMES, the National Medical Expenditure Survey. Starting in 1996, NMES (or MEPS, as it will be renamed) will be drawn from the NHIS sample and this will allow the linking of both the NMES and NHIS data files in the future.

Acknowledgment

The authors wish to thank Luong Tonthat, a programmer in DHIS, for producing the necessary data for this analysis.

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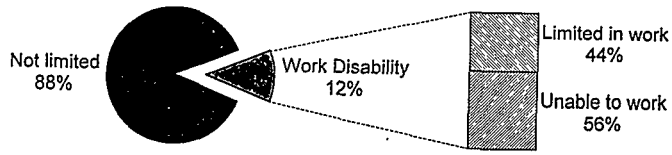
Table 1. Work Disability by Employment, Income, and Health Insurance for persons 25-64 years of age: United States, 1992

Characteristic	Total	Unable to Work	Limited in Amount/Kind Work	Not Work Limited
		Numbers		
Total	131,845,000	8,777,000	6,832,000	116,236,000
		Percent distribution by work disability		
Total	100	7	5	88
		Percent distribution by characteristic		
Total	100	100	100	100
Employment				
In labor force	79	18	78	84
Not in labor force	21	82	22	16
Income				
<$20,000	19	48	28	16
$20,000-34,999	21	15	22	22
>$35,000	44	16	35	47
DK	16	21	14	16
Health Insurance				
Private HI	70	38	64	73
Public HI	4	25	7	3
Other HI	2	13	4	1
No HI	16	17	19	15
DK	7	7	6	7

Figure 1

Work Disability

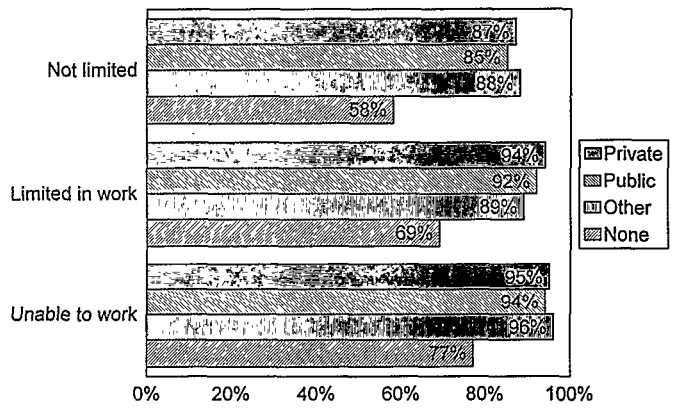
25-64 years



NHIS, 1993

Figure 2

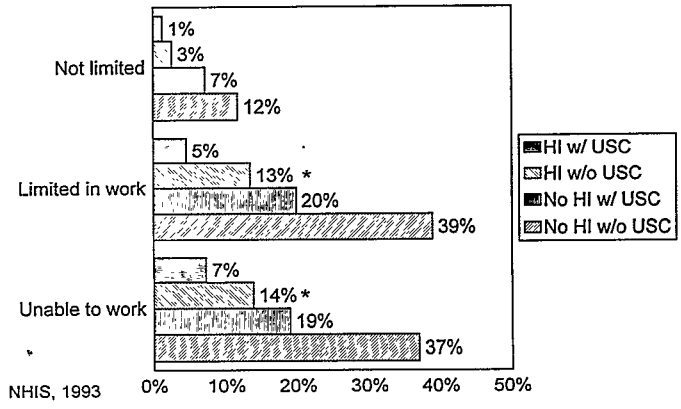
Usual Source of Care by Health Insurance



NHIS, 1993

Figure 3

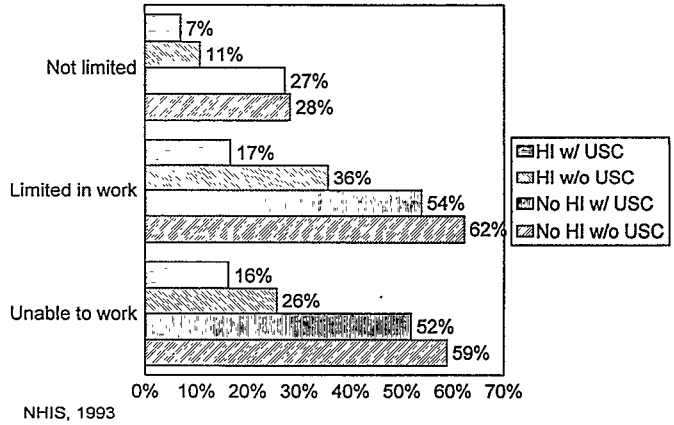
Not Getting Needed Care by Health Insurance and USC



NHIS, 1993

Figure 4

Delayed Care Due to Cost by Health Insurance and USC



NHIS, 1993

ACCESS TO HEALTH CARE AMONG PERSONS WITH DISABILITIES: CANADA

Adele Furrie, Statistics Canada

Paper not available for publication

SURVEY OF DISABILITY SERVICES IN STATE HEALTH DEPARTMENTS

Louis Rowitz, University of Illinois at Chicago

Paper not available for publication.

SETTING UP A SUSTAINABLE MODEL SYSTEM FOR DISABILITIES SURVEILLANCE: RHODE ISLAND, A CASE STUDY

Joann M. Lindenmayer, Brown University School of Medicine
John P. Fulton
David Hamel

INTRODUCTION

The context in which we considered disabilities and its surveillance is changing. In the past two decades many common diseases and conditions have been reexamined and redefined. Among these are chronic diseases, injuries, and disabilities. In 1963, Webster's International Dictionary defined disability as **"deprivation or lack, especially of physical, intellectual, or emotional capacity or fitness, and the inability to pursue an occupation or perform services for wages because of physical or mental impairment."** In 1976, Stedman's medical dictionary defined disability as a **"medicolegal term signifying loss of function and earning power."** In 1991 the Institute of Medicine (IOM) defined disability as a **"limitation in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks and roles that individuals generally are expected to be able to do."** The first definition considers disabilities a defect in the individual, the second focuses on individual loss of function and earning power, and the last and most current definition acknowledges the role of health and the social environment in the establishment and maintenance of a disability.

Political forces have shaped and continue to shape disabilities prevention programs. Federally-funded disabilities prevention programs were created in the late 1980s under a categorical funding scheme. Recent changes in the political environment will usher in an era of block grants. Programs that address noninfectious diseases and conditions will not only be forced to compete for funding, but the total amount of funding will be considerably less than it has been.

The changing definition of disabilities and the changing political climate will have wide-ranging effects on state disabilities programs and on surveillance for disabilities. We will use the experience of the Disabilities Prevention Program in Rhode Island to illustrate these points.

AN OVERVIEW OF THE RHODE ISLAND DISABILITIES PREVENTION PROGRAM

Rhode Island's Disability Prevention Program (RIDPP) was established in 1991 by funding from the Centers for Disease Control and Prevention (CDC). The program's original focus was twofold - the primary prevention of injuries to children and facilitating linkage of children to services.

Because the RIDPP is young it has only recently concluded the process of developing a strategic plan for preventing disabilities in Rhode Island. The focus of the strategic plan is **"preventing disabilities by managing impairments."** A plan for disabilities surveillance is included in the strategic plan, and this paper constitutes a first draft of that surveillance plan.

SETTING UP A DISABILITIES SURVEILLANCE SYSTEM IN RHODE ISLAND

Rhode Island has not been invested in the disabilities surveillance process long enough to be committed to a particular surveillance system.

General criteria for a surveillance system

In building a disabilities surveillance system we first considered four general criteria recommended for evaluating an existing surveillance system[1], namely

* the public health importance of the event,
* a description of the system, including its objectives, definition of events under surveillance, and its components and operation,
* the usefulness of the system and what actions might be taken as a result of the data, and
* an evaluation of the system for simplicity, flexibility, acceptability, sensitivity, predictive value positive, representativeness, timeliness, and the resources needed to operate it.

Specific surveillance issues related to disabilities

In addition to these general criteria we also considered the unique nature of disabilities surveillance.

It is necessary to adapt the medical model of surveillance for noninfectious diseases and conditions. Most surveillance systems have traditionally focused on counting occurrences of readily definable vital events and infectious diseases. This model of surveillance does not always meet the needs of noninfectious diseases and conditions. To illustrate one of the many problems associated with applying traditional surveillance system criteria to disabilities surveillance, consider that no easily standardized clinical or laboratory criteria can be used to establish the case definition of any particular disability. It has been said that "Although little disagreement exists over the concept of impairment, this is not true for the concept of disability, as persons who consider themselves to have a disability, professionals who study disability, and the general public disagree about its meaning. It is no surprise that if disability is perceived to mean different things to different people, demographic counts and estimates of the number of persons with a disability will also differ. [2]

It will be necessary to integrate surveillance for disabilities with surveillance for other programs such as chronic disease, injury control, and maternal and child health. Because disabilities prevention cuts across so many different programs, it has historically been integrated into other categorical programs. Under block grants there will be even more incentive to strengthen this integration in order to make data collection as efficient as possible.

Lastly, some measure of accountability must be built into disabilities surveillance systems. This process has already been applied to prevention block grants, which will make use of a uniform data set for this purpose. Disabilities prevention staff will need to make hard decisions about which features of disabilities to monitor. The Institute of Medicine model of disabilities suggests priorities for disabilities surveillance. These include enumeration of persons at points along the disability continuum and assessing the quality of their lives as measures of the burden of disabilities and as indicators of the success of disabilities prevention and intervention programs.

Assessing the current state of understanding of disabilities in Rhode Island

As the first step towards setting up a disabilities surveillance system, we undertook to answer the question, "How important a public health problem is disability in Rhode Island?" by reviewing what was known about the extent of disabilities.

From the 1990 Census, work limitation/disability among 16-64 year olds was 7% overall, and twice this prevalence was found in the cities of Providence, Pawtucket, and Woonsocket. Mobility/self care limitation among persons 65 years of age or older was 18.3% overall, and greater than 25% prevalence was found in the cities of Providence, Pawtucket, Central Falls, and North Smithfield.

Every five years, Rhode Island conducts the Rhode Island Health Interview Survey (RIHIS), a household survey modeled after the National Health Interview Survey. The 1985 RIHIS contained questions regarding activity limitation and established a baseline against which to measure changes in limitations. From the 1985 RIHIS it was determined that 3.8% of children under 5 years of age had any limitation of play activity, 10.4% of 5-17 year olds had any limitation of school attendance, 14.1% of 18-64 year olds had any limitation of work or other activities, and 33.2% of persons 65 years and older had any limitation of their capacity for independent living. In all age groups, the proportion with the most extensive disability ("unable to perform a major activity") was higher in Rhode Island than it was nationally.

Two years ago the RIDPP developed a Disability Databook[3] using existing data sets. Twenty six statewide data sets were reviewed for the following criteria:

* reliability,
* documentation,
* computerized,
* population-based,
* representative,
* collects age, gender, race and census tract,
* available annually from 1986 through 1990, and
* sufficient cases to calculate meaningful rates.

Two datasets - the Hospital Discharge Dataset (HDDS) and the 1990 Census - were chosen as the basis for the databook.

The authors next reviewed four national surveys that measured functional limitations, listed the top 10 disabling conditions for each survey, and created a comprehensive list of 21 disabling conditions. From these, 13 conditions associated with hospitalization were chosen for inclusion in the databook:

* five chronic diseases, including cerebrovascular disease, diabetes, arthritis, asthma, and colorectal cancer,
* three injuries, including traumatic brain/spinal cord injury (TB/SCI), hip fractures, and disc injury, and
* five indicators of developmental disabilities, including congenital anomalies, intrauterine growth retardation, prematurity, birth hypoxia/asphyxia, and newborn hospital length of stay longer than 7 days.

For every 1000 births, prematurity was the most prevalent discharge (70.3/1000) among those with some indication of developmental disability, followed by prolonged length of hospital stay (36.6/1000), hypoxia/asphyxia (19.7/1000), and intrauterine growth retardation (12.5/1000).

Among children less than 5 years of age, asthma accounted for 43.0 discharges/10,000 children and congenital anomalies for 38.5 discharges/10,000 children.

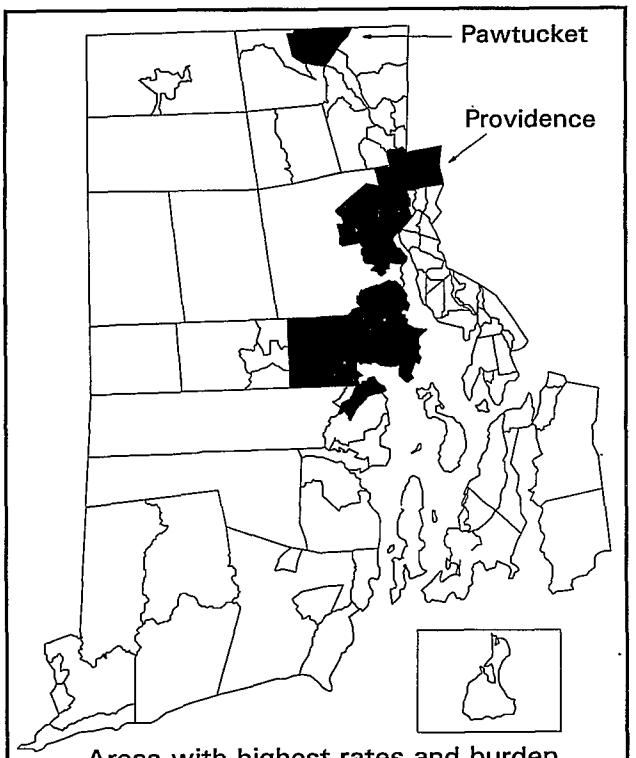
Among persons less than 19 years of age, traumatic brain and/or spinal cord injury accounted for 9.1 discharges/10,000 children.

Among adults 16-64 years of age, disc injury accounted for 22.1 discharges/10,000 adults.

Among adults 65 years of age or over, cerebrovascular disease accounted for the greatest number of hospital discharges (154.1 discharges/10,000 adults), followed by arthritis (44.8 discharges/10,000), diabetes (44.7 discharges/10,000), and colorectal cancer (37.6 discharges/10,000).

Lastly, among white women 65 years of age or over, hip fractures accounted for 93.4 discharges/10,000 women.

Census tracts of residence were combined into 14 geographic groupings, ranked by rate of hospital discharge and by the total number of people affected. The areas that ranked in the top half of all areas for both rate and burden are pictured in Figure 1. They include Providence and Pawtucket, areas previously described as having the highest rates of work, mobility, and self-care limitation.



Areas with highest rates and burden of disability-related hospital discharges
Rhode Island, 1986-1990

Figure 1.

Having completed preliminary analyses with existing datasets, we turned our attention to the choice of a model for disabilities.

Choice of a Model for Disabilities

For purposes of disabilities surveillance we chose to adopt the IOM model of disabilities with the following minor modifications (Figure 2):

* We added stages of wellness and death;
* We added arrows to indicate that progress along the continuum from wellness to disability is reversible to some degree;
* We regarded the attainment of each stage as a risk factor for progression to the next stage. Hence progression to any stage implies failure of risk management at the last stage. This is consistent with the RIDPP strategic plan.

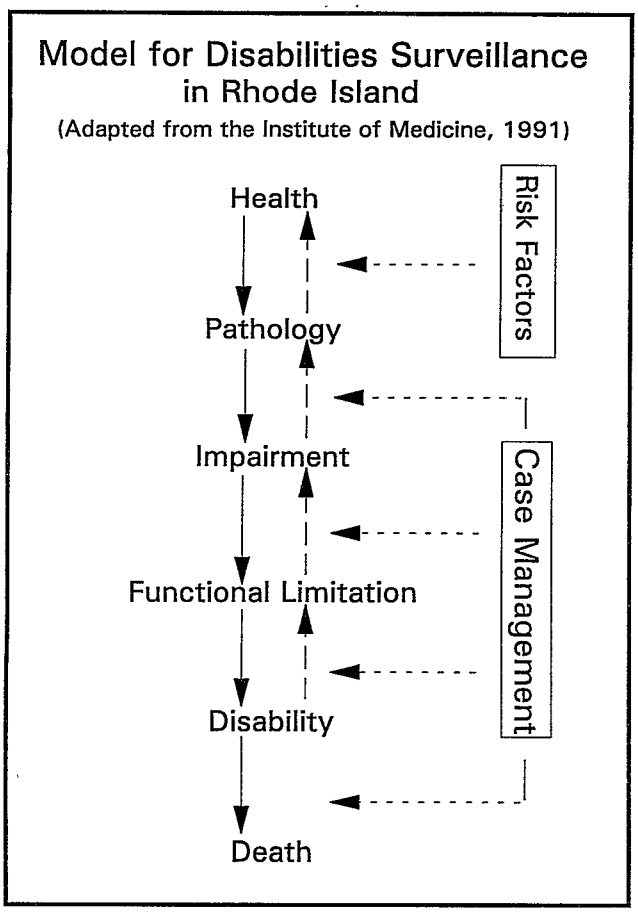


Figure 2.

Specification of the Surveillance System

We chose the "pathologic event/impairment stage" as the starting point for our surveillance system to limit its scope.

Keeping in mind that our strategic plan calls for case management (a combination of medical management and linkage to social services) as a means of preventing disabilities, we developed a matrix defined by age group and stage in the disabling process (Figure 3). It is possible to categorize current sources of disabilities surveillance data using these two criteria. For example, one surveillance source represented on the matrix is the TB/SCI registry. Currently, the registry identifies persons at the time of injury (pathologic stage), but provides no followup of potential progression along the disability continuum. People between the ages of 6 and 64 are those most likely to be registered.

Other current sources of disabilities surveillance data represented in the matrix include the comprehensive prenatal screening program (CPSP), newborn screening program (NS), early intervention program (EI), special education programs (SE), hospital discharge data set (HDDS), Rhode Island Health Interview Survey (RIHIS), and the Behavioral Risk Factor Surveillance System (BRFSS). The first four (CPSP, NS, EI, and SE) are linked together and to other datasets by the Rhode Island Children's Access Program (RICAP), a system that integrates public health responsibilities for universal newborn screening, outreach, home visiting, and follow-up through a central registry and automatic tracking system.

We used this matrix to assess the comprehensiveness and usefulness of our current surveillance sources. Several observations may be made:

* There are a number of diverse sources for disabilities surveillance, but most are not specific for disabilities.
* Although each age grouping is covered by at least one surveillance source, the disability continuum is best represented among children.
* Few linkages are found among datasets.
* Many datasets are limited to counting the occurrence of an event without follow-up.
* None of the sources address the needs of persons without telephones, most of whom have low incomes and are therefore at high risk of having or developing disabilities.

We used the matrix to identify a number of steps to improve the surveillance system:

* Better use can be made of some sources (e.g., TB/SCI) to follow persons prospectively through the disability continuum.
* Linkage of datasets should be considered, particularly among impaired adults, so that DPP services can be targeted and used more efficiently.
* Some sources (RIHIS, BRFSS) can be adapted to assess quality of life.
* Surveys should be developed to address the needs of those who are not under surveillance.

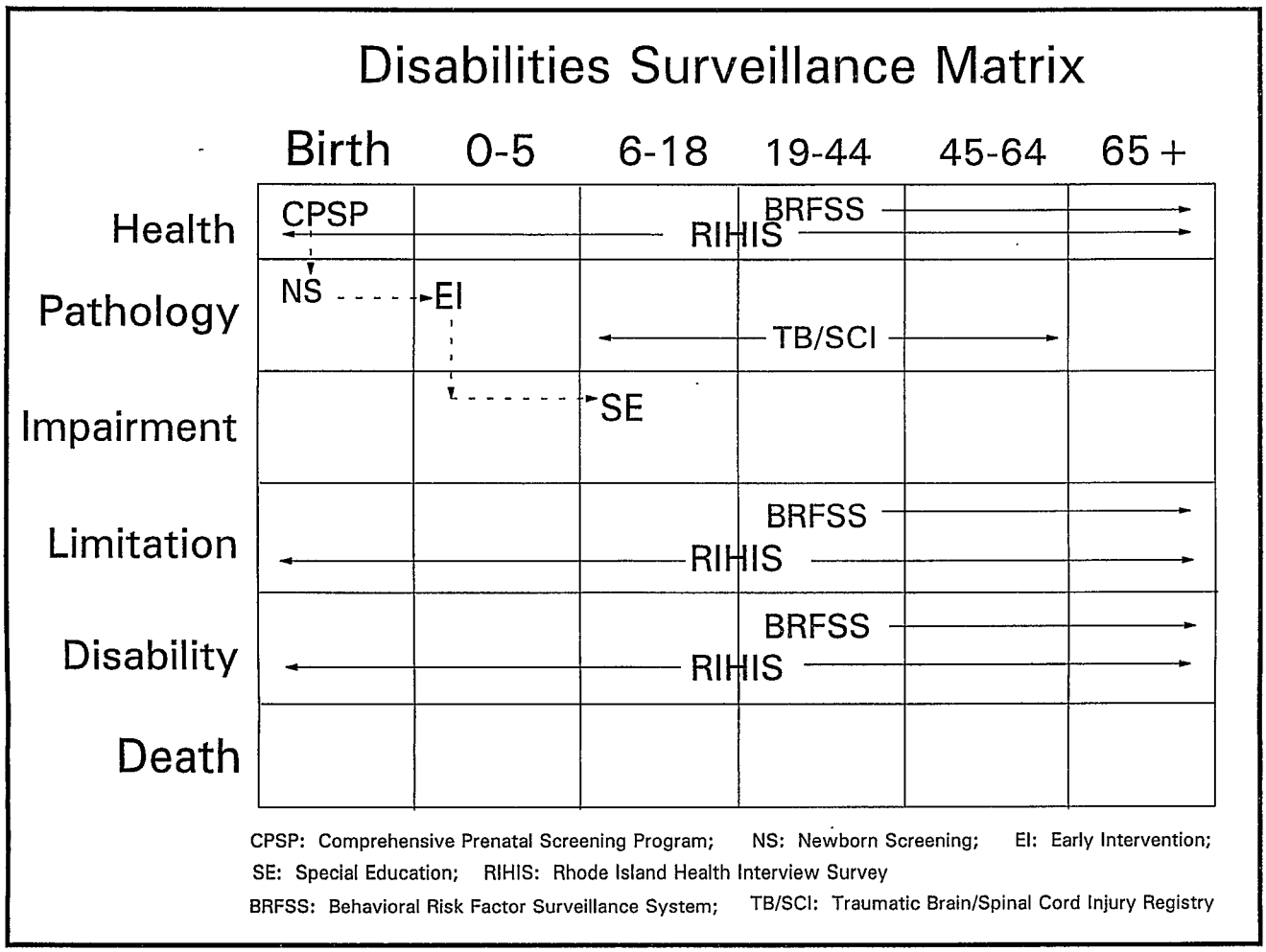


Figure 3.

CONCLUSION

This paper represents Rhode Island's first steps towards setting up a sustainable disabilities surveillance system. In order to accomplish this we must continue to challenge established notions about surveillance and to be responsive to the changing social and political environment.

References

1. Centers for Disease Control. Guidelines for evaluating surveillance systems. MMWR 37(S-5):1-18, 1988.

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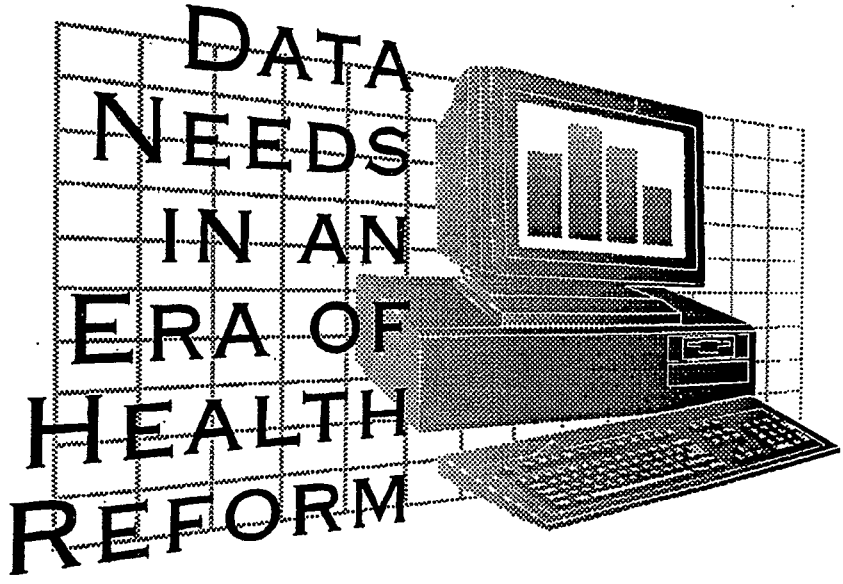
Session O

Methodological Issues II



A RECORDS - SURVEY COMPARISON OF ELIGIBILITY AND HEALTH CARE UTILIZATION MEASURES FOR MEDICAID BENEFICIARIES: ADULT AND CHILD REPORTS

Donna Eisenhower and Angela Schmitt, Mathematica Policy Research, Inc.

Background

This study is part of a larger effort to assess the feasibility of conducting a national survey of Medicaid beneficiaries. The study has been conducted by Georgetown University's Center for Health Policy Studies and Mathematica Policy Research under a grant from the Physician Payment Review Commission. A national survey is being considered to produce state-specific estimates and generate enough information for monitoring access-to-care. Many sampling and other survey design issues need to be evaluated to determine the feasibility of conducting such a survey.[1] This paper reports on an effort to assess the accuracy of survey estimates related to Medicaid eligibility and health care utilization for adults reporting for themselves and for adults reporting for one randomly selected child. The accuracy of the survey estimates will be assessed by comparing the survey data to Medicaid records data.

The survey data are the result of a pilot survey of Medicaid beneficiaries that was conducted in one northeastern state between August 1 and October 25, 1993. The survey resulted in 358 completed adult self-reports and 320 adult reports for one randomly chosen child. Medicaid records data were abstracted for these same individuals after waiting an additional three months to assure that any lagging medical claims were processed.

To conduct a national survey requires that eligibility information be accurately reported by survey respondents or collected from records. If the accuracy of the Medicaid eligibility determination is in question, all measures related to access or utilization will be meaningless if such measures are evaluated in terms of Medicaid participation. This matter is complicated in Medicaid populations where a portion of the participants have inactive or active eligibility (go on or off Medicaid) during the course of a year. Therefore, accessing the ability of respondents to report eligibility accurately is critical to evaluating the feasibility of using survey data or the related need of abstracting such data from records.

Secondly, the assessment of the accuracy of utilization measures provides a measure of accuracy in general and also provides a basis of assessing the feasibility of collecting accurate measures from a survey. Recall bias in collection of health care utilization measures is well documented in the literature.[2] The record-survey comparison will shed light on the need for the use of bounding or memory aids,[3] the appropriate recall period, the need for statistical adjustments of the estimates, or the need to use records data for certain measures.

The measures for which survey responses will be compared to records data for both the self-report of the adult and the adult report for the child include:

- Eligibility for Medicaid by month over the past year
- Number of doctor's visits for either last month or last three months[4]
- Date of admission for overnight hospitals stays
- Number of nights hospitalized

Results

Eligibility. Several measures of eligibility were assessed as part of the full study and are available as part of the final report. The most important eligibility question asked of survey respondents regarding eligibility was, "Now thinking back over the last twelve months beginning in July 1993 and ending in August 1992, please tell me to the best of your ability if your (then the child's) eligibility for Medicaid was active for every month during that year?" As Table 1 indicates, 91.8 percent of survey responses for adults matched the records data. Of these, 71.5 percent were active for all twelve months and matched and 20.3 percent matched but were not active for all twelve months. Of the 8.2 percent of responses which were mismatches, 4.8 percent mismatching was because the survey said they were active when the record data showed they were not, and 3.4 percent mismatching was because the record data said they were active and the survey said they were not. At 89.0 percent, the number of survey responses of the adult reports for the child was very similar to those for adult self-reports.

While this is a modest degree of mismatch, it should be improved if survey data alone is to be used to produce national estimates. Therefore, two subsequent analyses were conducted to examine the reasons for mismatch.

The first examined if recall bias explained the mismatches. If recall bias alone accounted for the mismatches, more mismatches should occur further back in time. While there was a pattern in that direction, it was not consistent for either the adult or child report.

The analyses explored the concept of "transition month" as a reason for the mismatch. The transition month is the last month either with or without Medicaid and the ensuing month where there is a change of status. An analysis of this phenomenon showed a mismatch rate for adults of 40.3 percent in transition months compared to a 10.3 percent mismatch rate in non-transition months.[5] Similarly, the mismatch rate for the adult report for a child was 33.3 percent in transition months compared to 10 percent in non-transition months. Clearly, the greater percentage of mismatches occur during a transition month when a Medicaid beneficiary may not even be aware that their official status has changed. Regarding eligibility status, lack of awareness rather than recall bias is more of an explanation. This actually suggests that the survey data may be adequate if the data users account for the transition month phenomenon when looking at other survey measures. However, the better alternative is to use eligibility data from records to supplement the other survey data.

Utilization

Doctor Visits. The first utilization question to be compared to records data read, "During the last month (or past three months), how many times did you see a medical doctor for an in-person visit?"[6] As mentioned, one-half the sample responded to a one-month recall period and one-half to a three-month recall period. The findings presented in Table 2 for adults indicate that for exact matches, the one-month recall is significantly more accurate with 51 percent of the survey responses matching records data compared to 26.9 percent for the three month-recall period.

When a match is defined reasonably as ±1 visit, 78.4 percent match for the one-month recall for adults while 58.2 percent match for the three-month. Of adults reporting, 83 percent reported 0, 1, or 2 visits within the last month (35 percent reported 1 visit). Within the last three months, of adults reporting 75 percent reported 0, 1, or 2 visits (42 percent reported 1 visit).[7]

Clearly, a one-month recall period for doctor visits for adults is preferred to a three-month recall period. In fact, if accurate estimates greater than ±1 visits are required, a two-week recall period may be necessary.[8] This, however would suggest that a larger sample size would be required. As Table 2 also indicates, when adult respondents err, more (80 percent) overestimate the number of visits at a one-month recall period while slightly more (55 percent) underestimate at a three-month recall period. This is evidence of some telescoping at a one-month period and some recall decay at three months. This also suggests that accuracy would be improved by the use of bounding techniques for either a one-month or two-week recall period.

As for most measures, there is at least slightly greater accuracy for adults reporting for a child than for adults reporting for themselves. As Table 2 indicates, exact matches for children were 57.6 percent for the one-month recall period and 50.6 percent for the three-month recall period. The most noticeable improvement for children is at the three-month period with 50.6 percent compared to 26.9 percent for adults. However, even 50.6 percent is less than the desired accuracy for survey estimates. When a match is defined as ±1 visit for children, the matches for children increase dramatically to 93.2 percent for the one-month recall period and to 78.5 percent for the three-month.

If a match is defined as ±1 visit for children, the one-month recall period provides a good survey estimate of the number of doctor visits. An exact match could probably be improved further by using a two-week recall period. Error for the one-month recall period is usually an overestimate of one visit suggesting telescoping. This problem can also be improved by the use of bounding procedures. Error for the three-month period is slightly more often (53.8 percent), an underestimate suggesting some recall decay.

Hospitalizations. The second utilization question asked, pertains to overnight hospitalizations and reads "Since July 1, 1992 a year ago, were you a patient in a hospital OVERNIGHT?" Hospitalizations are large events subject to telescoping in survey reporting. As Table 3 indicates, only 63.3 percent of the adult hospitalizations reports for yes/no responses matched records data. Most of this error is due to overestimating, suggesting the effect of telescoping in hospitalizations from a previous period or to less likely record error (some reports may be missing due to unexpected lags in billing). For those reporting "yes", they then answer the question, "How many different times did you stay in any hospital overnight or longer since July 1, 1992 a year ago?" As Table 3 indicates, 84.1 percent have exact matches on the actual number of hospital stays. Of these, all errors

were either missing one (8.7 percent) or two (7.2 percent) overnight stays. Therefore, getting more accurate estimates for adult hospitalizations requires increasing accuracy at the "yes" or "no" question. Perhaps asking the number of hospitalizations directly over the last year without asking a yes/no question first would in itself improve response accuracy.

For children, the accuracy in the yes/no response to the first question on whether hospitalized is almost equal to that for adults at 63.2 percent. Once again, most err in the direction of saying "yes" when the records suggest the correct answer is "no". The percentage of matches for the number of hospitalizations reported for children is 83.3 percent: again almost equally accurate to that of adults. When there is error in reporting the number of hospitalizations for children, most are underestimates off by one less overnight stay than the records indicate. Although this would be unusual, there may be an unexpected lag in the billing or reporting in the records accounting for this difference. Hospitalizations are large, infrequent events and for these the accuracy is more equivalent for both adult self-reports and adults reports for a child. For both adults and children, the clear majority (88% for children, 87% for adults) reported only 1 overnight stay in the hospital over the previous year.[9]

Questions during the hospitalizations were also asked as follows: "Since July 1, 1992 a year ago, on what date did you enter the hospital the last time? The time before that?" A high 94.8 percent of the month of hospitalization matched for adults. The match for the full date which included the day was 70.7 percent. The correct match for the number of nights of hospital stays was 56.9 percent for exact match and 86.2 percent if a match is defined as ±1 night. The survey question for this reads, "For the stay beginning (READ DATE), how many nights were you in the hospital?" The respondents interpretation or perception of days verses nights in the hospital may be the source of error for this question. If they were in the hospital for a substantial part of a day, they might want to report this as an overnight's stay. In other words, the respondent may want to get credit for staying in the hospital and want to actually report "days" in the hospital.

There was an approximately equal percentage of matches on month of hospitalizations for children as adults at 93.3 percent. There was a much better match on the full date of hospitalization for children at 90 percent. The exact match on number of nights stay for children was 53.3 percent (slightly less than that for adults) or 83.3 percent, if the ±1 night criterion for match is used.

Conclusion

The survey literature supports the premise that eligibility and health utilization measures will be subject to recall bias in respondent reporting in **any** population, including a poorer, less educated one. In fact, the literature suggests the recall error increases proportionately with the length of the recall period for such measures. The findings from this record check study support these premises for utilization measures. However, error in respondent reporting for eligibility status is better explained by the lack of awareness of their status during a one to two month transition period rather than to recall bias. Certain measures of eligibility and utilization data are more critical than others to a national survey of Medicaid beneficiaries and accuracy in these measures should be emphasized.

Whether the respondent was actively on Medicaid over the entire 12-month period is critical information. The match of survey to records data is much higher than the noncritical for this critical information at 91.8 percent for adult report and 89 percent for the child report. However, this information is so critical that it needs to be even closer to a 100 percent match to dismiss the problem. A subsequent analysis indicated that mismatch in survey response error was largely due to a transition month phenomenon which resulted in lack of awareness of the respondent as to their Medicaid status. Recall bias was shown to be less of a problem for respondent reports of eligibility for both the adult and child. Therefore, accuracy in respondent reports of eligibility may be sufficient to support the purposes of the national survey, but better still is to use eligibility data from records to supplement survey data.

Depending on the emphasis on the national survey, precise utilization measures may be less critical than this eligibility information. The one-month recall period for doctor's visits was a better match (more accurate) for both adult and child reports, but substantially better for adult reports. If the match is defined as ± 1 visit, the match is improved dramatically, especially for child reports. The three-month recall period for doctor visits is of poor accuracy for adult reports and not adequate but better for the child reports. The one month recall period introduced telescoping in of visits, the three-month period was subject to recall decay. These findings suggest that accuracy in reporting

doctor's visits may be optimum at a 2-week recall period, especially if used with bounding procedures to reduce the effect of telescoping.

The reporting for hospitalizations is good at 83-84% marker for the number of hospitalizations occurring during the past year. However, hospitalizations are rare events (the majority of adults and children only reported 1 hospitalization) in this young population and should be reported more accurately. The greatest source of error was in the initial question which asked whether or not there was a hospitalization during the previous 12 months. Only 63 percent of the adult and child reports matched the record. Furthermore, the accuracy was highest at around 93-94% for the reporting for month of occurrence. These findings indicate that asking the more specific information on hospitalizations first will improve the accuracy of reporting. Certainly, skipping the question on whether hospitalized in favor of asking the number of hospitalization should reduce error in respondent reports. Finally, the accuracy of reporting of number of nights stayed was not good and might be improved by emphasizing "nights" not "days" in the hospital.

Accuracy of utilization measures need to be improved by either shortening the recall period; using memory aids and bounding procedures (a costly alternative); or by supplementing survey data with records data. It is important to keep in mind that while these measures are subject to recall bias, there are other critical measures such as access to care or satisfaction measures which will be asked on a national survey. Because these measures do not involve precise frequency of event reporting, they are not likely to be subject to the recall problem to this extent. Recall bias is more problematic in behavioral frequency questions.

ENDNOTES

1. See "Assessment of Access to Care Pilot Survey of Medicaid Beneficiaries" by Eisenhower et al., Physician Payment Review Commission, November 24, 1993.

2. A review of the literature is available as part of the final report.

3. Bounding involves presenting some information gathered from one period for a respondent to that respondent for a subsequent survey. Memory aids include the use of checklists, flashcards, maps, pictures, and calendars.

4. The survey sample was randomly assigned to either a one or three month recall period.

5. Complete tables are available as part of the final report or upon request.

6. The probe read "Include all types of doctors, such as dermatologists, psychiatrists and ophthalmologists, as well as general practitioners and osteopaths. Do not count times while an overnight patient in a hospital.

7. This data is not presented in a table but reported from a separate report.

8. A two-week recall period was not tested as part of this study.

9. Again, this data is not reported in a table but elsewhere in a separate report.

TABLE 1

MEDICAID ELIGIBILITY FOR ALL MONTHS–AUGUST 1992 TO JULY 1993

Adults	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Match Not Active[1]	59	20.3	59	20.3
Match Active[2]	208	71.5	267	91.8
Mismatch Survey Active	14	4.8	281	96.6
Mismatch Record Active	10	3.4	291	100.0

Frequency Missing = 5

Children	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Match Not Active	69	22.3	69	22.3
Match Active	207	66.8	276	89.0
Mismatch Survey Active	20	6.5	296	95.5
Mismatch Record Active	14	4.5	310	100.0

Frequency Missing = 5

[1] This is a match where the respondent said they were not actively on Medicaid for all 12 months.
[2] This is a match where the respondent said they were actively on Medicaid for all 12 months.

TABLE 2

SUMMARY STATISTICS ON MISMATCH/MATCH FOR ONE MONTH AND THREE MONTH RECALL OF DOCTOR'S VISITS - ADULT AND CHILD

I. ADULT SELF-REPORT

A. One Month Recall - Adult	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Mismatch	25	49.0	25	49.0
Match	26	51.0	51	100.0
Magnitude -				
Minus	4	16.0	4	16.0
Plus	21	84.0	25	100.0
B. Three Month Recall - Adult				
Mismatch	49	73.1	49	73.1
Match	18	26.9	67	100.0
Magnitude -				
Minus	27	55.1	27	55.1
Plus	22	44.9	49	100.0

II. ADULT REPORT FOR THE CHILD

A. One Month Recall - Child	Frequency	Percent	Cumulative Frequency	Cumulative Percent
Mismatch	25	42.4	25	42.4
Match	34	57.6	59	100.0
Magnitude -				
Minus	6	24.0	6	24.0
Plus	19	96.0	25	100.0
B. Three Month Recall - Adult				
Mismatch	39	49.4	39	49.4
Match	40	50.6	79	100.0
Magnitude -				
Minus	21	53.8	21	30.8
Plus	18	46.2		100.0

TABLE 3

A. HOSPITALIZATION: ANY OVERNIGHT STAYS DURING THE PAST YEAR (YES/NO RESPONSE)

Adults	Frequency	Percent	Cumulative Frequency	Cumulative Percent
I/P CLAIM NO SURVEY	12	11.0	12	11.0
NO I/P CLAIM MATCH	28	25.7	40	36.7
I/P CLAIM MATCH	69	63.3	109	100.0

Children	Frequency	Percent	Cumulative Frequency	Cumulative Percent
I/P CLAIM NO SURVEY	6	10.5	6	10.5
NO I/P CLAIM MATCH	15	26.3	21	36.8
I/P CLAIM MATCH	36	63.2	57	100.0

B. HOSPITALIZATIONS: OF THOSE SAYING "YES," DEGREE OF MATCH OF OVERNIGHT STAYS

Adults	Frequency	Percent	Cumulative Frequency	Cumulative Percent
2 Less than record	5	7.2	5	7.2
1 Less than record	6	8.7	11	15.9
EQUAL	58	84.1	69	100.0

Children	Frequency	Percent	Cumulative Frequency	Cumulative Percent
1 Less than record	5	13.9	5	13.9
EQUAL	30	83.3	35	97.2
5 More than record	1	2.8	36	100.0

USE OF CASE MIX DATA TO MONITOR THE IMPACT OF TENNCARE

Jim Shmerling, LBCMC
Maren Proulx

On January 1, 1994, the State of Tennessee implemented a dramatic effort in health care reform entitled "TennCare." TennCare is a five-year demonstration project that utilizes managed care organizations to contract health care for the previously eligible Medicaid population as well as the uninsured.

In addition to a significant projected cost savings, the TennCare program was intended to provide affordable comprehensive coverage for virtually every Tennessean. It received the Health Care Financing Administration's (HCFA) approval in November 1993 and was implemented in January 1994.

There has been significant criticism specifically related to the underfunding of the program and its hurried implementation. However, to date there has been limited clinical analysis of TennCare's impact on its intended beneficiaries. In an effort to assess the impact of TennCare on its pediatric population, Le Bonheur Children's Medical Center utilized the National Association of Children's Hospitals and Related Institutions' (NACHRI) Case Mix Comparative Database.

Le Bonheur Children's Medical Center is a regional referral center with 225 beds. Its primary and secondary service area includes portions of Tennessee, Mississippi, Arkansas, Missouri, Kentucky and Alabama. More than 100,000 children receive treatment on an inpatient or outpatient basis every year.

NACHRI's Case Mix Database is built on pediatric inpatient medical record abstracts from over 50 children's hospitals, and hundreds of teaching and nonteaching facilities. The medical record abstract data were available by ICD-9-CM code for both principal and secondary diagnoses.

NACHRI and Le Bonheur limited their analysis to the data of high-volume patient populations, specifically those admitted with a respiratory principal diagnosis (PDX). The authors reasoned that by using selected diagnoses that represented high volumes of both Medicaid and non-Medicaid patients, existing trends could be identified while still identifying external influences, such as whether there was a light or severe year for RSV respiratory infections for children. These data could then be used to mirror the overall impact of TennCare on the patient population of Le Bonheur.

The analysis looked at the principal diagnosis of each respiratory patient, the age of the patient, and whether there were any congenital and chronic conditions (often reflected through secondary diagnoses). The analysis included all patients with a respiratory principal diagnosis who were one week or older at time of admission. For all of these patient breakouts, the analysis examined whether the patient treatment included mechanical ventilation (an indication that the patient was severely ill) or a major or extreme complication as identified through the APR-DRG classification system. Finally, for all these breakouts, the analysis provided length of stay and cost (operating and capital) statistics.

NACHRI has developed a method of mapping approximately 2,000 of the ICD-9-CM codes into a series of over 60 congenital and chronic child health conditions. The system was developed to track the small proportion of the pediatric population that is the sickest: those who require specialized health care services and expend the most health care dollars. The application of these flags was particularly important in measuring the Respiratory PDX population before and after TennCare. For example, while many pediatric patients are admitted with pneumonia, the patients with chronic secondary conditions such as bronchopulmonary dysplasia, congenital heart anomalies, cerebral palsy, HIV or blood disorders will require disproportionate care and health care dollars. NACHRI's Congenital and Chronic flags allowed the reviewers to track these resource-intensive patients whose principal diagnosis may not have identified them as high acuity.

With these tools in hand, NACHRI and Le Bonheur began a review of its pre- and post-TennCare medical Respiratory PDX admissions. One of the principal philosophical underpinnings of TennCare was to provide low-income children access to primary and preventive care prior to the point at which they would require hospitalization. The authors sought to determine the impact that introduction of TennCare in 1994 had on admissions of Respiratory PDX patients comparing 1992 and 1993 data with 1994.

They found that in 1994, there was a significant decrease in the overall volume of Respiratory PDX from the average of the two years prior. The total decrease was approximately 27 percent for Medicaid and 46 percent for non-Medicaid patients, suggesting that 1994 was not a high-volume respiratory infectious disease year for the Memphis area. The case volume for Asthma and Pneumonia NOS (not otherwise specified), representing over 60% of the total Respiratory PDX, decreased for the Medicaid population 14.5% and 8.4% respectively while the non-Medicaid population decreased 39.5% and 35% respectively. The number of admissions for Bronchiolitis, most often caused by RSV infection, decreased by more than 50%.

Among those medical inpatients with Respiratory PDX, there was a 20% increase in admissions of TennCare children with chronic respiratory conditions. Hospitalized patients with a Respiratory PDX who have "other congenital and chronic" conditions remained the same for Medicaid patients. The pattern for non-Medicaid patients is different in both instances showing significant decreases in respiratory admissions for chronically ill children.

The most dramatic change in the first year of TennCare was in the length of stay and average operating costs for this population. Medicaid Respiratory PDX patients with congenital and chronic conditions experienced a sharp increase in costs associated with their care along with increases though less pronounced in the average length of stay. Costs for TennCare patients with chronic respiratory conditions nearly doubled from the average of the same Medicaid patients of the prior two years. Costs for TennCare patients with other congenital and chronic conditions increased by 20% in the year after TennCare. In contrast, non-Medicaid patients demonstrated a decline in both length of stay and costs associated with the care of respiratory patients who have congenital and chronic conditions.

The authors concluded that TennCare did not appear to have a positive impact in promoting the health of children particularly those with chronic and congenital respiratory conditions. In fact, hospital admissions and length of stays for these at-risk children increased and were more prolonged suggesting a higher acuity and corresponding higher costs for their care. This phenomenon occurred in a period of time when there was an overall decline in the Respiratory PDX population admitted to the Hospital and when the non-TennCare patients actually experienced a lower utilization of services.

Additional studies of these populations are anticipated. The Case Mix Data System will enable Le Bonheur to conduct control studies of its most at-risk patients. Medicaid managed care is being proposed as an integral component to health care reform. However, its impact particularly on vulnerable children is not known. As this study indicates, a Medicaid managed care product may not reduce health care costs or improve the health status of pediatric enrollees. Because a primary motivation for Medicaid managed care is cost containment, additional research is imperative to identify the clinical impact as well as the financial. NACHRI's APR-DRG classification system and its classification of congenital and chronic conditions provides the means to evaluate changes in inpatient case mix. The Case Mix Data System will serve as the source of data for future analysis of TennCare's impact on patients served by Le Bonheur. In addition, because there are several other children's hospitals in Tennessee who also participate in the Case Mix System, comparative studies can be conducted on a state-wide basis.

RESPIRATORY PDX

Age > 1 Week Old

Congenital and Chronic Conditions, e.g.:

- Bronchopulmonary Dysplasia
- Congenital Heart Anomalies
- Cerebral Palsy
- HIV
- Other Blood Disorders

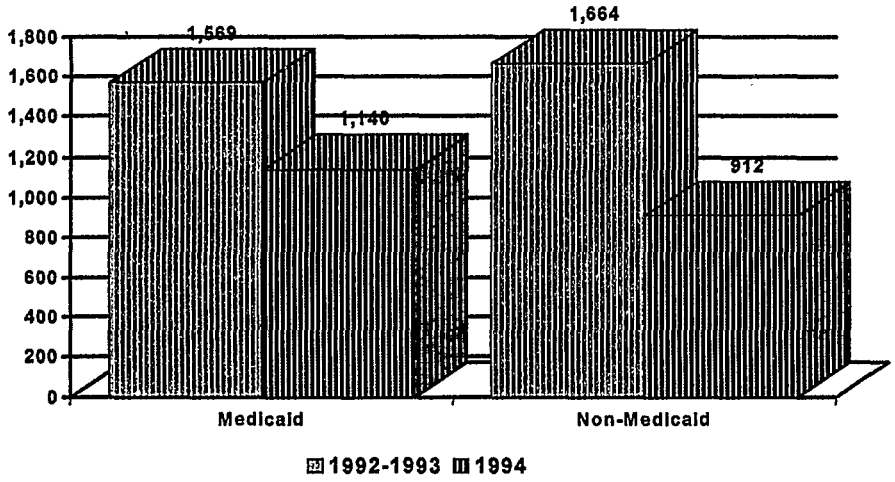
Mechanical Ventilation

Major or Extreme Complication per APR-DRGs

Length of Stay

Costs

CASES of inpatients with a Medical RESPIRATORY PDX



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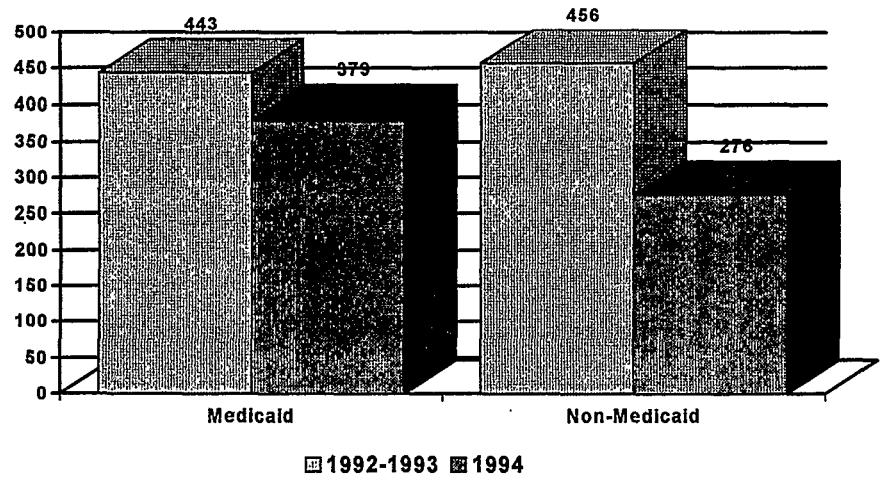
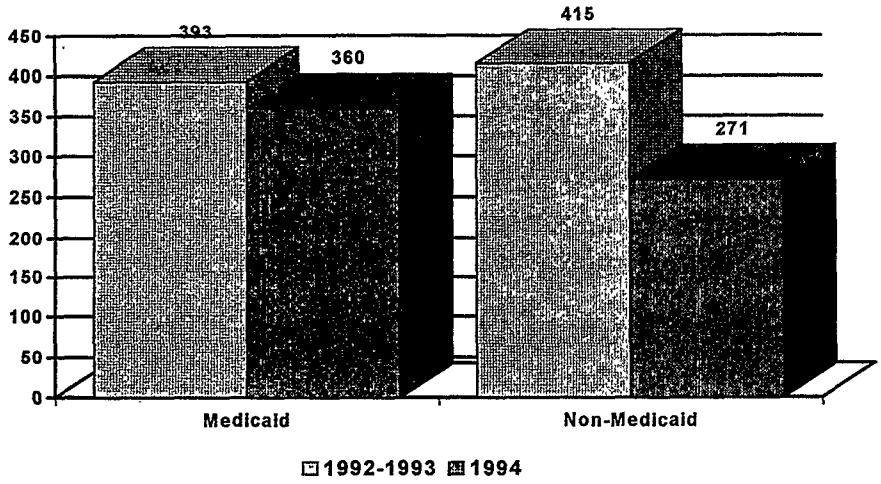
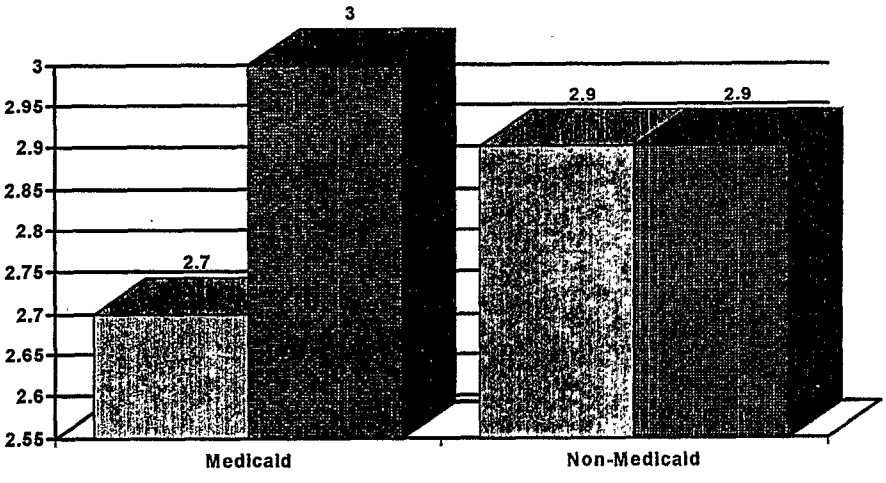


CASES of inpatients with a Medical Respiratory PDX of PNEUMONIA NOS



ALOS for All INPATIENTS with a Medical RESPIRATORY PDX



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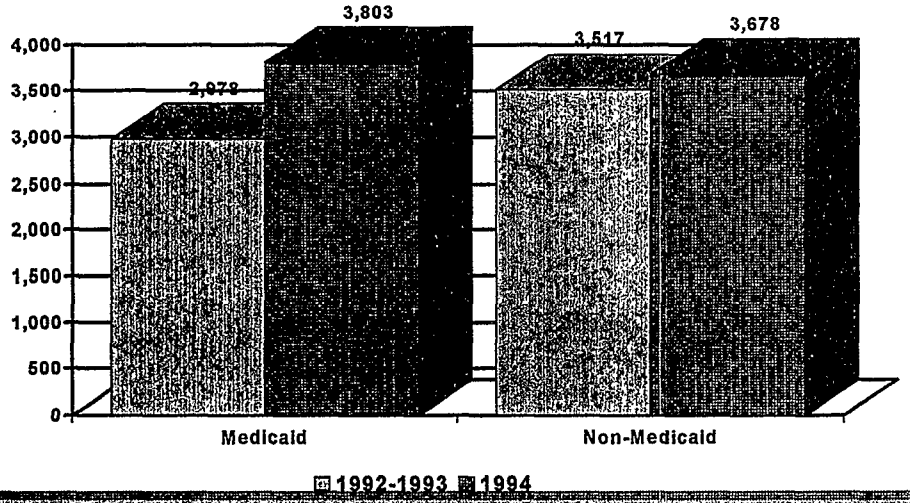
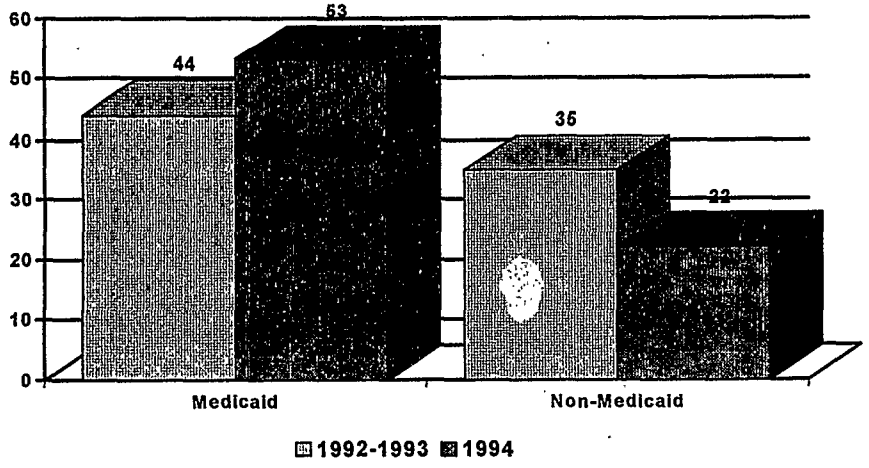


NUMBER OF CASES Chronic Respiratory Conditions



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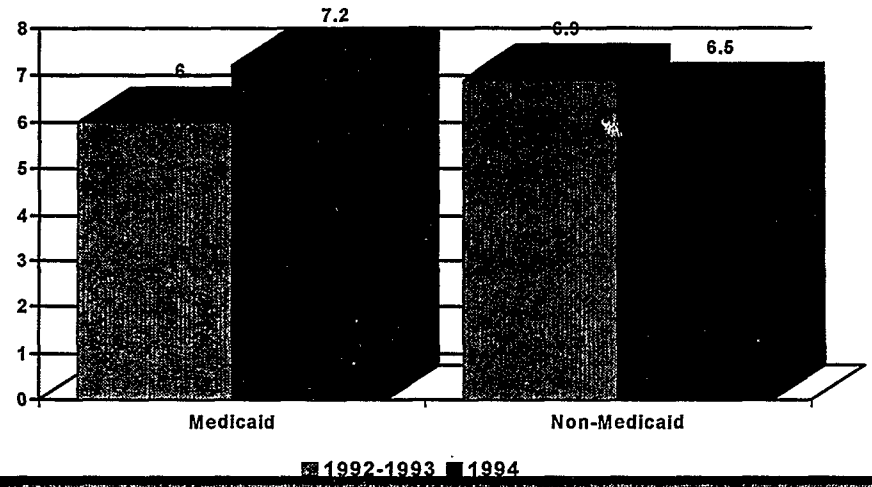
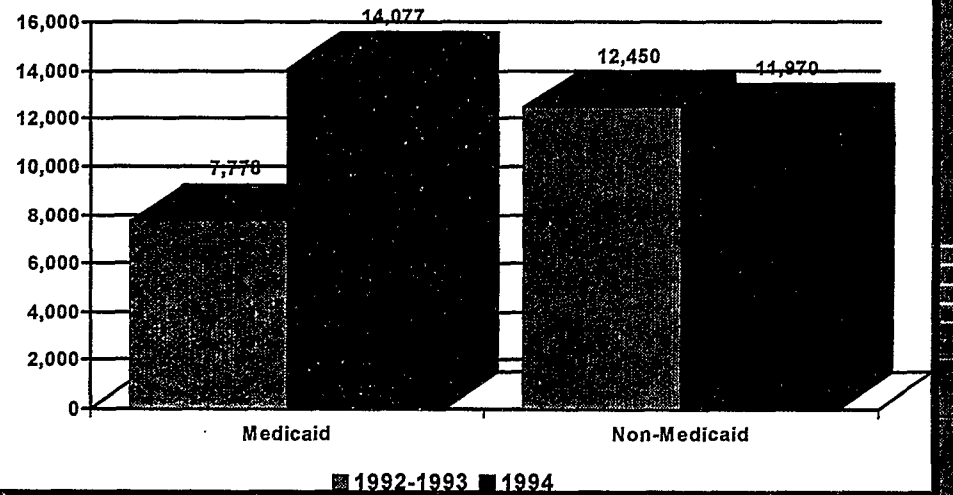


AVERAGE OPERATING COSTS for All Inpatients with Chronic Respiratory Conditions



20TH CENTURY ALCHEMISTS: GENERATING RESEARCH DATA FROM A BILLING DATABASE

Lynne Fullerton, University of New Mexico
M. Jack Lee, Lenora Olson, David Sklar

Introduction

The appropriateness of health care utilization, and the cost of emergency care, is of concern in a time of health reform. One aspect of emergency services, prehospital care, has only recently become the focus of research related to health care utilization. The only national, industry-specific journal dedicated to prehospital research is *Prehospital and Disaster Medicine*,[1] first published in 1985. Our understanding of prehospital medicine is also limited by the fact that prehospital medicine has changed considerably in the past three decades. EMS was initially promoted and developed to treat and transport critically ill patients, such as cardiac arrest patients and those with potentially fatal trauma, to emergency departments.[2,3,4] Health care needs have changed such that prehospital care is now less often involved in the treatment of fatally ill or injured persons, and more often involved in the treatment of patients for whom emergency department care may not be required.

Injury data sources available at national and local levels focus primarily on mortality statistics, data available from police reports, and injuries associated with particular injury sites (e.g., the National Head and Neck Injury Registry) or mechanisms (e.g., the Boating Accident Reporting System).[5] Few data sources exist to examine non-fatal injuries, and it is particularly difficult to follow the course of an injury from prehospital services through the ultimate outcome.

There are currently no national data sources available to evaluate the use of prehospital services for emergency care and utilization patterns. The National Uniform Data Set for EMS, under the auspices of the National Highway Traffic Safety Association (NHTSA), proposes to begin to address this need. This data set is being developed to collect national injury data and related EMS call information to aid research in traffic-related injuries. This database is an example of how injury tracking may benefit from the use of prehospital data.[6]

Prehospital data provide an epidemiologic window onto community patterns of non-fatal injury and illness for which ambulance transport occurs. Whereas specific hospital data may be biased by payer class, location, or expertise of the hospital, data from ambulance transports to multiple hospitals provide an overall picture of certain medical problems in a community. Ambulance data have traditionally been utilized for quality assurance and billing purposes, and are a relatively untapped resource in disease and injury research. We attempted to use these data to provide epidemiologic information concerning medical conditions that have not previously been well defined from a community context.

To examine prehospital care in a large, urban community, we used data collected by the primary ambulance service for this community. These data can be used to examine ambulance utilization patterns over time, and to suggest alternatives to possibly unnecessary ambulance use.

Methods

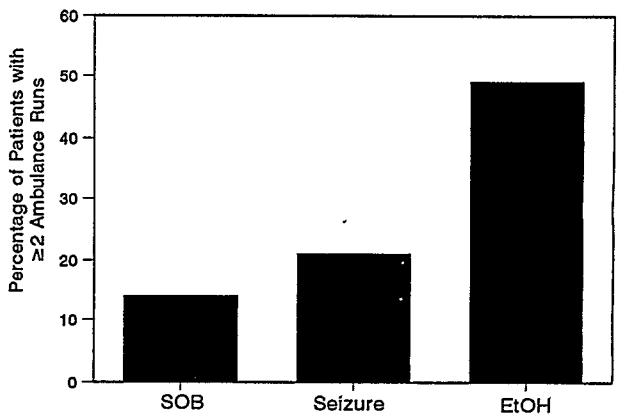
We used a propriety billing software (MedOccur™), an AMOS METROPOLIS™ database, with the following features: built in pre-structured reports; no flat file or relational capacity; and, no ad hoc querying or reporting capacity. From this database, we created an artificial relational database by downloading hardwired reports, limiting the number of records by downloading records restricted by parameters such as year of transport and diagnosis.

The steps in the translation process were as follows: 1) we printed the MedOccur™ reports to a spooler file, creating an ASCII file; 2) using an AlphaMicro™ interface, we downloaded the ASCII file to a personal computer; 3) using a spreadsheet program, we imported the ASCII file and converted it to a database program; and 4) we manipulated the data and translated various coded fields to create a database compatible with research.

Results

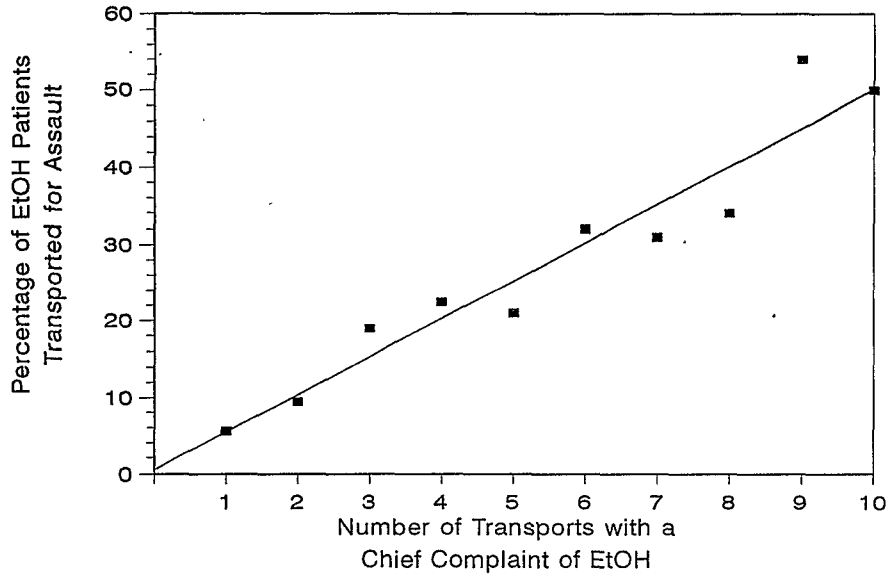
Since the inception of our collaboration, we have developed several databases to study a variety of prehospital issues. In our first project, we compared numbers of diagnosis-specific transports among patients transported for acute alcohol intoxication (EtOH), seizures (Sz), and asthma/shortness of breath (SOB). We found that the proportion of patients transported two or more times for the same chief complaint was highest among EtOH patients, among whom nearly half (49%) had been transported more than once, contrasted with 21% of Sz patients and 14% of SOB patients ($p < .0001$) (Figure 1). The results of this study will be used to examine the efficacy of alternative prehospital treatment protocols for acutely intoxicated patients who have no other emergent conditions. These data may also be used to study the cost-effectiveness of constructing and staffing a detoxification/alcohol treatment center in our community.

Fig. 1: Percentage of Patients In Each Diagnostic Category Who Were Transported Two Or More Times For The Same Chief Complaint, AAS data, 1992-1994



In our second project, we examined the association between ambulance runs for acute alcohol intoxication (EtOH) and ambulance runs for assault. We found that the proportion of EtOH patients who also had assault transports increased with increasing frequencies of EtOH transports ($ß=4.9$; $R^2=.92$) (Figure 2). Our finding that over half (56.6%) of patients transported ten or more times for EtOH had been transported on another occasion for assault has clear implications for violence prevention interventions.

Fig. 2: Percentage for EtOH Patients Transported with a Chief complaint of Assault as a Function of Number of EtOH Transports, AAS data, 1992-1994



In addition to injury research, we have also collaborated on a project evaluating response times to cardiac arrest calls by response levels, using the Emergency Medical Priority Dispatch System (EMPDS). Using 1994 cardiac arrest data, we found that the large majority of cases were dispatched with the highest level of response (n=284; 93.1%). Our study demonstrated that the EMPDS is highly accurate with regard to cardiac arrests. Future research will evaluate the EMPDS with respect to outcomes other than cardiac arrests.

Discussion

The most important result of our collaboration was the development of an ongoing research group dedicated to examining issues related to public health and prehospital medicine. This project combined the expertise of a medical school department of emergency medicine and the primary ambulance service for the area to design and conduct multiple projects relevant to prehospital research. Our projects are unusual in that they provide an insight into nonfatal injuries and disease in the community.

The results of our research have many potential applications. One use of our collaborative projects concerns quality control and evaluation of existing prehospital protocols. Other prehospital research has been used to evaluate the utility of traditional prehospital interventions such as treatment of hyperventilation; the results of such research have indicated that the potential consequences of this intervention may exceed the benefits.[7] Similarly, our data have been used to evaluate response times to cardiac arrests cases associated with EMPDS response levels. Our study of repeated ambulance use will be expanded and used to suggest new trends in prehospital care such as treat-and-refer, rather than the current method of treat-and-transport. Such changes have the potential to increase the efficacy of prehospital care, while at the same time reducing the costs associated with unnecessary use of emergency rooms. These projects provide us with information we can use to advocate for changes in medical services in the community as has been done previously by groups promoting EMS in primary health care.[8] One example of collaboration involving such groups is the annual

Sandkey conference which focuses on the role of EMS in the delivery of primary health care.[9,10] The Sandkey conferences have included individuals from several disciplines, including EMS, nursing, and medicine. Recommendations resulting from Sandkey conferences have included: 1) customizing programs to build alliances and collect health data; 2) adding/ increasing components such as disease prevention and health education to EMS; and 3) using EMS for home health care delivery, including assessment, diagnosis, and follow-up. Another recommendation was to develop treat-and-refer protocols to supplement the currently used treat-and-transport protocols.

Our collaboration has benefited both organizations involved in the research. The ambulance service now has the necessary data to evaluate the efficacy and cost effectiveness of various EMS treatment interventions and alternatives. Our research has also prompted the ambulance service to investigate available software that will permit development of customized data queries and reports. The use of this software will obviate the need to have reports generated within the current operating system, ultimately saving hundreds of dollars per report. The emergency department has benefited in terms of access to a powerful and rich source of data for faculty and residents' research and community projects. These data have provided baseline and long-term information on injury morbidity for planning effective injury prevention initiatives.

Currently, research such as ours is the only way to access community level non-fatal injury data. However, efforts are underway both nationally and in New Mexico to link databases from multiple sources relevant to injury research. We anticipate that the Crash Outcome Data Evaluation System (CODES) projects initiated by NHTSA will begin to address the need for non-fatal injury data in the nation.[11,12,13] The purpose of the CODES projects is to link injury data from police records, emergency departments, coroners, and hospital discharge data to obtain a complete picture of the injured patient in our health care systems. CODES projects are currently operating in several states, and already have provided excellent results. In New Mexico, the data linkage system is still in the process of development, and it is not expected that data will be available from the New Mexico CODES project until 1997.[14] In the meantime, data from projects such as ours can be used to address the need for information concerning non-fatal injury in our state.

We have encountered limitations in the use of software not originally designed for research. The use of a non-industry standard operating system was associated with limited technical support. The software does not support standard querying language (SQL) queries, and as such we were limited to the customized reports prepared by the software vendor for the purposes of billing. Finally, the software does not create a relational file type database, which made it difficult to generate databases with fields located in more than one report. These limitations are being addressed by the introduction of software designed to interface with the AMOS METROPOLIS™ database and permit development of customized queries and reports.

We also found sources of error. Selection of ICD9 codes by paramedics was influenced by use of a "cheat sheet" to fill out the ambulance run form, i.e. a reference sheet that lists the most common ICD9 codes and abbreviated descriptions of the complaints associated with these codes. We found that the codes on the reference sheet

were used preferentially by some personnel, even when other ICD9 codes might have been more appropriate. This may have biased some of our findings related to diagnosis-specific outcomes. There were also some errors associated with manual data entry. We plan to address these sources of error through the introduction of computerized charting, to be introduced within the next year at the ambulance service. This technology permits the paramedics to enter the patient's complaint in the computer, and the associated ICD9 code is automatically entered. This system will eliminate the need for both the cheat sheet and the manual data entry.

Conclusion

Our research group provides us with an ongoing collaboration that allows us to investigate topics of interest to both organizations. The first year of our work together has generated multiple databases allowing us to examine myriad prehospital issues. We have developed software translation protocols and programs that will facilitate the creation of future research databases. In addition, we are investigating available software that will permit us to investigate a broader range of prehospital issues by allowing us to incorporate variables from all reports into one database.

This research has demonstrated that it is feasible to utilize a database developed and maintained for billing purposes to create databases amenable to prehospital research. The availability of these data will permit both retrospective and prospective study designs at a moderate cost. The resulting data and collaborative effort can be used to guide future decisions about prehospital health care delivery in our community.

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THE COST EFFECTIVENESS OF LINKED STATE DATA FOR HIGHWAY SAFETY

Dennis E. Utter
National Highway Traffic Safety Administration

By being at this conference, I think we all are demonstrating that we believe data are necessary for making sound decisions. Policy makers and program managers need quality data to decide which programs are needed and where they need to be implemented. After implementation, programs need to be evaluated to determine if the desired effect was achieved.

The need for data is especially true in administering highway safety programs. Each year, millions of dollars are spent trying to convince people to wear safety belts, use motorcycle helmets, cross streets at cross walks, not to drink and then drive, drive safely through construction zones, obey speed limits and traffic signals, and on and on.

The need for programs like these is demonstrated by data that provide us with the knowledge that motor vehicle crashes on the nation's highways take a staggering toll each year:

- More than 40,000 people are killed;
- More than 3,000,000 people are injured, 400,000 severely;
- Motor vehicle traffic crashes are the largest single cause of injury and death for persons under the age of 40; and,
- More than $137 billion in economic costs.

The toll in pain and suffering and in economic loss due to motor vehicle crashes is large. Reducing this toll is a national priority.

Despite the availability of these overall numbers, the data which a highway safety analyst at the state or local level can use are often extremely limited. Decisions upon which at risk populations are identified, countermeasures are developed, and safety program dollars are spent are often based upon feel rather than factual evidence. Evaluation of program effectiveness is as often based on the number of brochures handed out, or television spots made, as on whether the crash or injury rate declined or the cost of hospital care for injured victims was reduced as a result of the program.

The primary highway safety database available in most states is an electronic data file compiled from information collected at the crash scene by the investigating police officer. Every state requires that a report be filed when a crash occurs, if some minimum amount of property damage resulted from a crash or if an involved person was injured. These reports are collected by a central agency in the state which then creates a statewide, electronic database.

These statewide police reported crash data are an excellent source for many highway safety needs. They provide statewide characteristics about motor vehicle traffic crashes, the vehicles involved in them, and, to some extent, the people involved. From this file, highway safety analysts can obtain information about the number of crashes, identify where they occurred, and count the number of people killed and injured for different crash configurations and vehicle types. Data from police crash files on the number and characteristics of fatal crashes have been used by states, and by NHTSA, for many years to identify and evaluate highway safety countermeasures. In fact, highway safety programs have concentrated on reducing fatalities. Safety programs and motor vehicle crashworthiness improvements have steadily reduced the crash fatality rate. People are now surviving crashes who would have been killed 15 or 20 years ago. Consequently, safety programs are beginning to emphasize injury prevention and reduction and health care cost reduction.

This is where police crash data begin to fall short. Police data lack a description of the injuries, and their consequences, that the people involved may have received. Police reports can tell us if an involved person was killed. Most reports provide a classification for how severely a victim is injured, i.e., seriously injured, slightly injured, or not injured. Even these classifications are often inaccurate and vary between and among police jurisdictions. And, because the police officer is not a diagnostician, there is no way for him or her to know what particular injuries a victim sustained or what it cost to treat those injuries. For highway safety program identification and evaluation to be effective in injury control and cost reduction, better information on the types, the severity, the treatments, and the cost of the injuries sustained by those who survive a motor vehicle crash is needed.

The collection of information is not a trivial matter, either in design or in cost. To establish a new system to obtain information about the medical outcomes of persons injured in crashes would not be likely in this era of declining resources. But, we at NHTSA believe this information can be obtained in an efficient and cost effective manner. Patient specific data are being collected by different types of health care providers for numerous other reasons. If data files created from these sources could be linked to the occupant specific police reported crash data, medical outcome data could then be associated economically with specific crash data.

NHTSA has been exploring this concept since the late 1980s. In the Sensitivity Index Project, the states of Maine and Missouri were able to link their crash, Emergency Medical Services reports, and hospital discharge summary files to

evaluate EMS performance. The linkage methodology employed in these projects, however, was labor intensive and time consuming because it required exact matches. Such a procedure would be impractical on a large scale.

In 1991 NHTSA was provided with an opportunity to improve on the file linkage technology available to the states. The Intermodal Surface Transportation Efficiency Act of 1991 (ISTEA) instructed NHTSA to conduct a study using state data to evaluate the benefits of safety belts and motorcycle helmets in terms of mortality morbidity, severity and costs. To conduct such a study using state data, NHTSA concluded that the data needed to be statewide and, therefore, would be based on police crash data. Because data describing the injury severity and treatment costs of the injured people were necessary, the only way to obtain these data was to link the crash data to available medical outcome data files.

In 1992 NHTSA funded seven states to link their crash data files with medical outcome data files. NHTSA entitled this project the Crash Outcome Data Evaluation System (CODES) project. Exhibit 1 depicts the data files which could be linked in a CODES project.

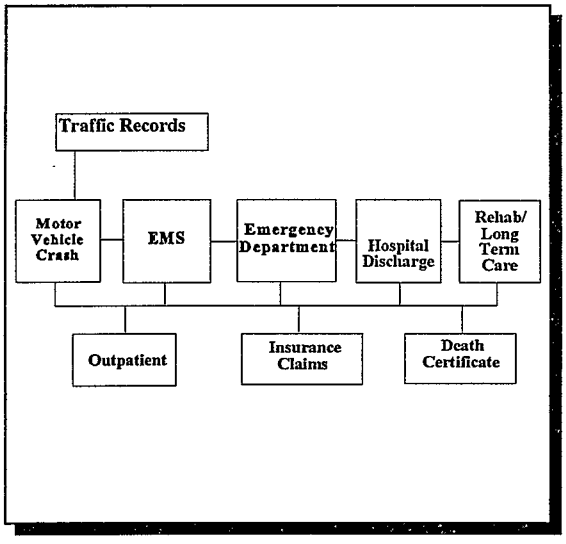


Exhibit 1. Crash and Injury Data Sources.

The files available in most of the CODES states were the emergency medical services, hospital discharge, long term care and rehabilitative care data files. Three of the states had emergency department data files and four linked to insurance claims databases. Even though each of the seven states differed in which data files were available, they all were able to link and obtain results which supported the required analysis

NHTSA elected to have the states in the CODES project use probabilistic linkage, a procedure which was first proposed by Fellegi and Sunter in 1969. The computer software developed using this procedure mitigated the problem of dealing with large file sizes.

The seven states were successful in linking their available databases. They have provided their linked data to NHTSA and performed analyses which have contributed to a draft Report to Congress on the Benefits of Safety Belts and Motorcycle Helmet Use which is available to the general public. I'll briefly summarize some of the results of this study.

NHTSA chose to evaluate the benefits of safety belts and helmets in terms of effectiveness. Effectiveness is defined as the percentage reduction in injuries or deaths for people wearing safety belts or using helmets. For example, if belts are 35 percent effective in reducing fatalities, 35 percent of the persons who were killed while not wearing belts would not have been killed had they been wearing a safety belt. An overall estimate of effectiveness was obtained by statistically combining the results of logistic regression analyses conducted by the CODES states. Exhibit 2 summarizes the effectiveness of safety belts and of motorcycle helmets by severity of outcome.

Exhibit 2.
Effectiveness of Safety Belts and Motorcycle Helmets by Outcome Measure for Crash-Involved Drivers and Motorcycle Riders in the CODES States

Outcome Measure	Effectiveness	
	Safety Belts	Motorcycle Helmets
Died	89%	33%
Died or Inpatient	75%	24%
Died, Inpatient, or Transported	54%	23%
Any Injury	50%	5%

These overall results confirmed previous NHTSA analyses that safety belts and motorcycle helmets are effective in reducing mortality and that safety belts are effective in reducing morbidity. Although motorcycle helmets are less effective at reducing morbidity, keep in mind that they were designed to protect the brain and not prevent most of the other types of injuries that a motorcycle rider could sustain. Therefore, NHTSA conducted another analysis that confirmed that motorcycle helmets were 67 percent effective at preventing brain injuries.

None of these analyses would have been possible without data on EMS transport, emergency department treatment, or inpatient treatment. The information for an accurate assessment of the injury severity which was necessary for the different effectiveness evaluations was not

available on the crash file. The analysis of motorcycle helmet effectiveness for preventing brain injury could not have been conducted without being able to identify the type of injury sustained by inpatient motorcycle riders. Linking files obtained these data.

Cost of treatment is extremely difficult to obtain. The cost data available in the CODES project were inpatient charges. NHTSA statistically combined average inpatient charges from each of the CODES states to produce overall average charges for belted and unbelted occupants and helmeted and helmeted drivers. In both cases, the average inpatient charges for those drivers or riders electing not to use the protection equipment were significantly higher. These results are shown in Exhibit 3. Without being able to link to the hospital discharge or inpatient files, data on charges would not have been available.

Exhibit 3.
Average Inpatient Charge by Protection Equipment Use for Inpatient Passenger Vehicle Drivers and Motorcycle Riders, in the CODES States

Group	Protection Equipment		Increase for Nonuse
	Used	Not Used	
Passenger Vehicle Drivers	$8,174	$13,144	61%
Motorcycle Riders	$12,374	$15,447	25%

Data linkage has obvious advantages. The data in the police crash database is enhanced. When linked, these data can be used for many more analyses than they could when the medical outcome data were not associated with the involved persons.

But there were other advantages which were not anticipated at the onset of the CODES project. To accomplish linkage, data files must be scrutinized in detail. This led to standardization of similar data items on the various files. Additionally, this detailed review of the data was often the first exhaustive look at some of the databases. This led to many quality improvements in the data. In one state, the data processing contractor was replaced when the poor job being done was discovered. Finally, each state convened an advisory committee of owners and users of the data. Often, this was the first time many of these people had collaborated on projects.

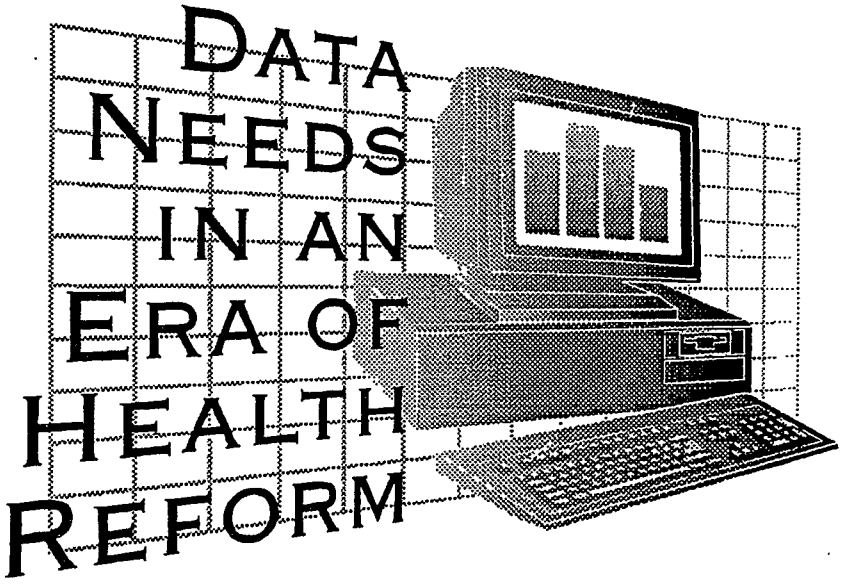
What's next in data linkage? NHTSA's vision of injury control for highway safety needs environmental, cause of injury, and medical outcome information that is useful to identify problems, develop programs and set and evaluate priorities. To get this information NHTSA is encouraging states to develop their own CODES. We believe that injury control in highway safety needs data such as that which can be provided from a CODES.

Many states are not able to develop a CODES, however. They lack one or more of the necessary medical outcome data files -- EMS, emergency department, hospital discharge. Three states even lack a statewide, computerized crash database. So, many states need to be encouraged to create these databases. In the meantime NHTSA will be promoting the advantages of these databases, their linkage, and their use. Information about CODES and results from the analyses performed by the CODES states will be presented at conferences and workshops. We will be making expertise gained by the CODES states available to those states who need it to get started. A contract is being developed to allow new states to request this input.

Obviously, there is a long way to go before a significant number of states have this resource available to them. We believe it is a necessary tool for future highway safety analyses.

Session P

Monitoring access to Care



ACCESS TO HEALTH CARE: KEY INDICATORS FOR POLICY

Janet B. Mitchell, Center for Health Economics Research

Paper not available for publication.

DEALING WITH THE BASELINE: WHERE DO WE START IN MONITORING ACCESS IN STATES

Marsha Gold, Mathematica Policy Research

Lauren Burnbauer and Karyen Chu

ABSTRACT

This paper presents selected findings from a 1994 telephone survey of policymakers in all 50 states funded by the Robert Wood Johnson Foundation and fielded in January--March 1994. The focus is on findings relevant to understanding where we start in having adequate data to monitor access to health care in each state. Doing so is likely to become increasingly important over time as policy authority gets decentralized to the states and interest grows in understanding how changes in both the public and private health systems, such as funding cutbacks and managed care, affect access to health care services across the nation.

In sum, the results indicate that states vary substantially in the information they have to monitor access but also that there are serious limitations in the access measures available in each of the states. For example, state policymakers cannot easily tell the number and characteristics of those without coverage in the state since most rely on national surveys which generally were not developed for this purpose. Virtually none of the states has data on how satisfied consumers are with health plans or with the quality of care in these plans. At a time when changes in the role of public health departments in delivering primary care are being considered, the majority or more of state health department respondents do not have very much confidence in data showing an unduplicated count of clinic users or the alternative sources of care available to clinic users.

Identifying which of these gaps are most important and how to address them should be a priority health policy issue at the national level, both to allow monitoring against national health access objectives and also to support states in carrying out their responsibilities.

SUMMARY OF PRESENTATION

Rationale for This Study

Current trends in the health care system are likely to make the monitoring of changes in health care particularly important over time, especially at the state level. States play an increasingly important role in addressing a complex array of health policy issues and challenges. These include tensions created by efforts to use the Medicaid program to promote access in an era of escalating costs; the resurgence of traditional public health issues associated with infectious disease and poverty; long-standing concerns with prevention, health promotion, and the development and distribution of health care personnel facilities and services; and newer concerns relating to integrating public and private efforts to handle these issues.

Appropriate tools, including data and analytical capability, are an important part of the infrastructure through which policymakers can address these challenges. Yet, the quality and sophistication of these tools vary considerably from state to state, and critical weaknesses are apparent in even the most advanced states. In addition to limiting what states can accomplish, these shortcomings lessen the ability nationally to monitor changes such as in access that vary across states in response to differences in both health care market trends and state policy.

This paper aims to (1) assess both policymakers' confidence in data relevant to access and the characteristics of available data; (2) assess funding trends and barriers to improving the utility of data; and (3) identify the key policy issues related to enhancing data for monitoring access.

Survey Design and Methods

The results in this paper are based on a telephone survey of key senior state officials in the legislative and executive branches of all 50 states and the District of Columbia.[1] The interviews were conducted between January and March 1994 by executive interviewers in the Survey Center at Mathematica Policy Research.

Interviewers were conducted by telephone with senior health policy advisors in eight functional areas: governor's health aide, health analysis for legislative committees (up to two in each state); central budget department staff dealing with health programs; a health reform entity, that is, the lead agency or task force charged with responsibility for health reform; Medicaid agency policy analysis; public health agency policy analysis; vital and population-based health statistics; and the database commission or other agency responsible for health resource and utilization analysis. Responses were received from 442 of 452 potential respondents, with at least seven responses for each state.

Survey content varied by respondent. All were asked a core set of items on their confidence with data relevant to their concerns and other issues. The first three (governor's aides, legislative aides, and budget staffers), termed "central policymakers," were asked about their perspectives across a range of issues. The last five were asked about their areas of concern and were also asked to provide factual information about data the state actually collects in their area of responsibility. In discussing the survey findings presented here, we indicate for each set whom the relevant respondents were.

FINDINGS

Central Policymaker Confidence in the Ability of Health Data to Address Priority Health Issues. We asked central policymakers to rank 12 issues in terms of priority in early 1994 (Figure 1). Of the 12, five were clearly dominant in early 1994: Medicaid, cost containment, access to care and the uninsured, maternal and child health, and managed care. State officials were most confident in data on Medicaid, followed by maternal and child health. Less than 10 percent were very confident about data available on the other three issues—all of which, in different ways, are important in examining access (Figure 2).

Data on Insurance Coverage, Expenditures and Health System/Plan Performance in the State. Governor's aides, legislative aides, and health reform staffers were asked about their confidence with state-based data on: health insurance coverage, health expenditures, and health system/health plan performance. These were viewed as "very important" by 87%, 98%, and 73% of state respondents.

Overall, few respondents (less than 10%) perceived any of the insurance coverage data to be excellent and over half perceived each type to be no better than fair (Figure 3). Aggregate data on the total percentage uninsured in the state generated more confidence than any of the other kinds of data. Factual reports by health reform staffers show that most states appear to rely on national data sources for information on insurance coverage, even though only one source at best (the

Current Population Survey) is designed for this purpose. The quality of state-collected data appears very uneven.

Confidence in health expenditure data was much greater for services provided in hospitals or by state government than overall (Figure 4). Virtually none of the states good confidence in data on total consumer out of pocket spending. These results are consistent with the structure of data collection currently in each state. Reports by health resource/database staffers show, for example, that reporting is much more extensive for hospitals and other facilities than for community based providers and practitioners, few of whom report any but perhaps the most basic provider characteristic information (Table 1).

Confidence with data on different measures of health system and plan performance was lowest of the three areas examined, with few states having better than fair confidence in data on quality of care for plans or providers or consumer satisfaction with care or insurance (Figure 5).

Data on Public Health Services. Figure 6 shows the relative confidence of public health respondents in each state about specific kinds of data we perceived might help them decide if funding for public health clinics should be reduced as part of state budget funding. Confidence was most on the ability to identify the number of clinic visits in the past year. It was least on the ability to identify alternative sources of care for clinic users and on the effects of the clinics on health outcomes. An inability to obtain and especially to link information on individual services provided to different patients, in different clinics, or in different jurisdictions probably is one reason such information is hard to obtain (Figure 7).

Barriers to Improving the Availability and Quality of Data. The three biggest barriers Medicaid, public health, resource/database and vital statistics respondents view in improving data are lack of comparability across datasets, funding, and gaining submission of data from providers and insurers (Figure 8).

Trends and Fiscal Issues. Sixty-eight percent of all respondents surveyed perceived that the ability of health data to meet policy needs had improved from three years ago, while 7 percent felt it was worse, and 25 percent saw no change. At least as of early 1994, data did not appear to be losing funding relative to general cutbacks, but the cuts have had some negative effects: 84 percent of states reported more pressure on staff, and 34 and 26 percent reported a reduced scope of analysis or timeliness of reporting.

CONCLUSIONS AND POLICY ISSUES

State data systems and the confidence policymakers have in them reflect the history of state health programs and sources of support. States appear relatively confident in data that supports ongoing operations of stable programs such as monitoring Medicaid or operating individual public health programs. However, state data systems are not perceived as being well-suited to supporting assessments of program needs or to guiding decisions about restructuring health care systems in a changing environment.

The findings suggest that serious gaps exist in data potentially of great value in monitoring access across or within states. Particularly in today's fiscal climate, it is important to identify priorities. What data are needed across all states? These clearly have national priority, the key issue being to decide which need to be collected centrally and which by each state. How to structure and finance such data initiatives also are key, particularly when budgets are being cut back and the desirable data probably are substantially in excess of that which can be financed. Nationally, there could be a need to consider trade-offs between depth and breadth. Having comprehensive national data systems has contributed to enhanced understanding of access in the U.S. Perhaps, at the margin, some depth could be sacrificed to support larger sample sizes that can better support state-specific and timely estimates of key measures. Given the changing policy context, having such information could be of growing importance.

REFERENCES

1. For more information on survey methods and findings, contact the authors for papers entitled "Miss or Match: How Well Do State Data Systems Support State Health Policy Needs"; and "Half Empty or Half Full: The Capacity of State Data to Support Health Reform."

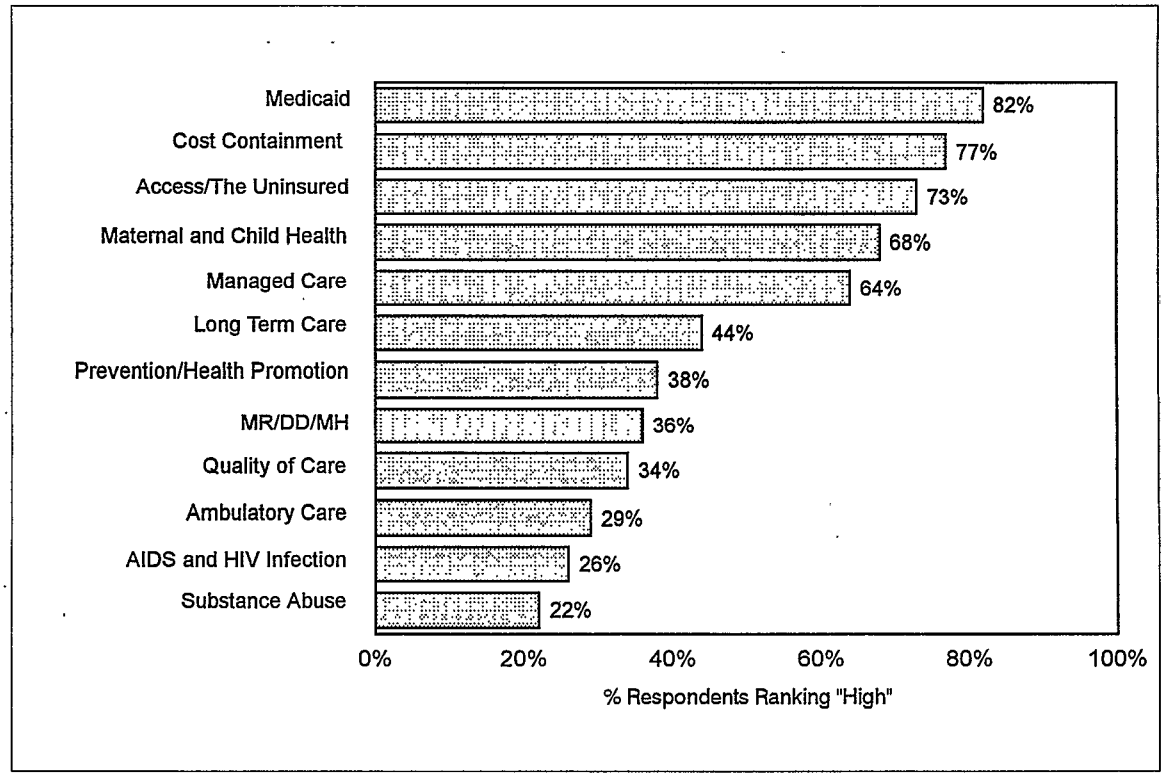
2. Strategies for improving state health data are further discussed in Penny Feldman, Marsha Gold, and Karyen Chu, "Enhancing Information for State Health Policy," *Health Affairs*, Summer 1994, pp. 236-250.

Table 1. Characteristics of Data States Collect From Providers

			Number of States That Collect by Data Type				
	% Any	(N)	Any	Provider Charac-teristics	Aggregate Use	Finance	Pt. Level Discharge/ Encounter
Acute Care Hospitals	92	(51)	47	33	40	36	38
Ambulatory Care Facilities	51	(51)	26	19	18	16	16
Licensed Clinics	30	(50)	15	11	7	7	8
Physician	53	(51)	27	25	5	1	6
Nurse Midwives	34	(50)	17	14	3	1	4
Physician Assistant	37	(51)	19	16	1	0	2

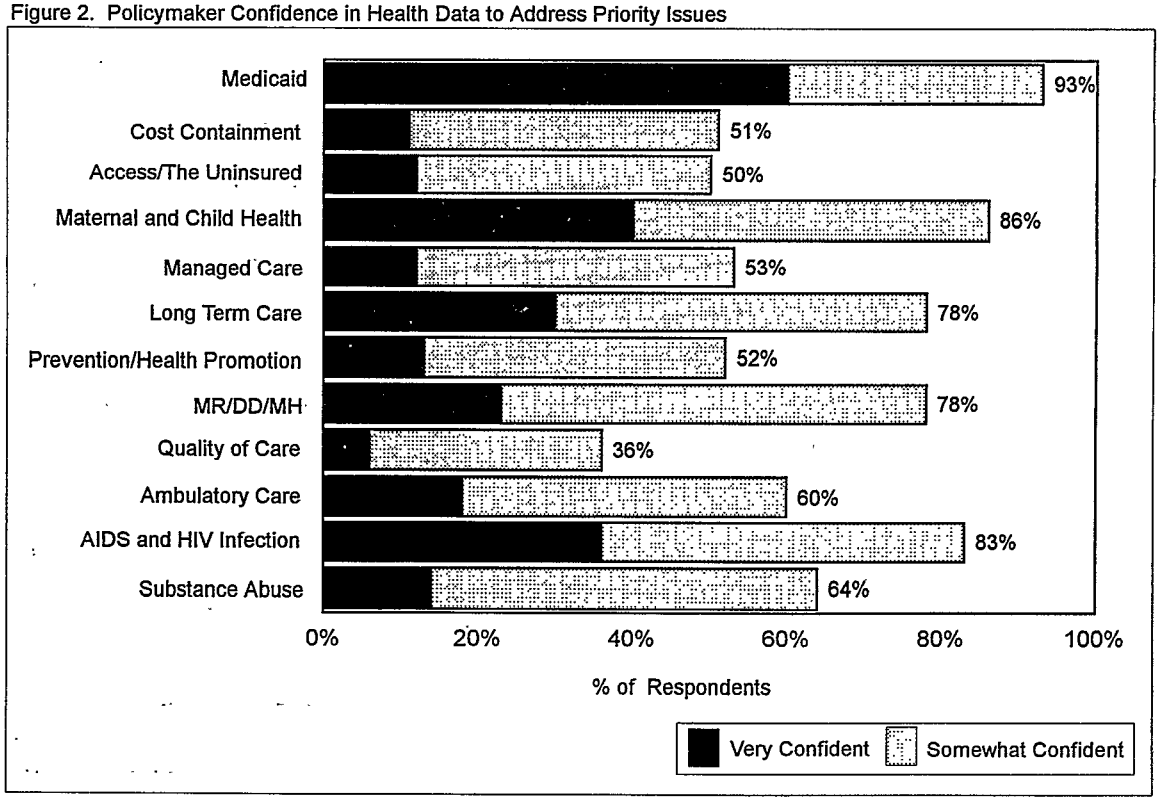
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.

Figure 1. Health Issues Ranked by Priority



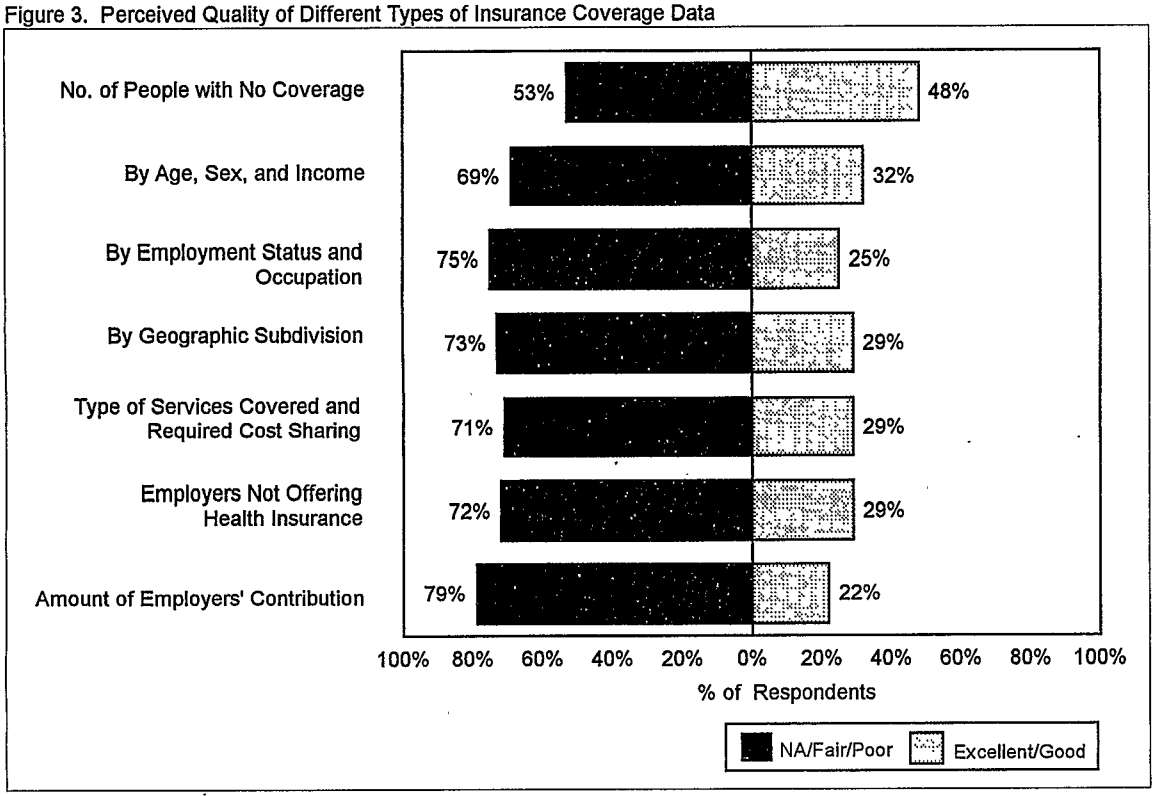
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.

Figure 2. Policymaker Confidence in Health Data to Address Priority Issues



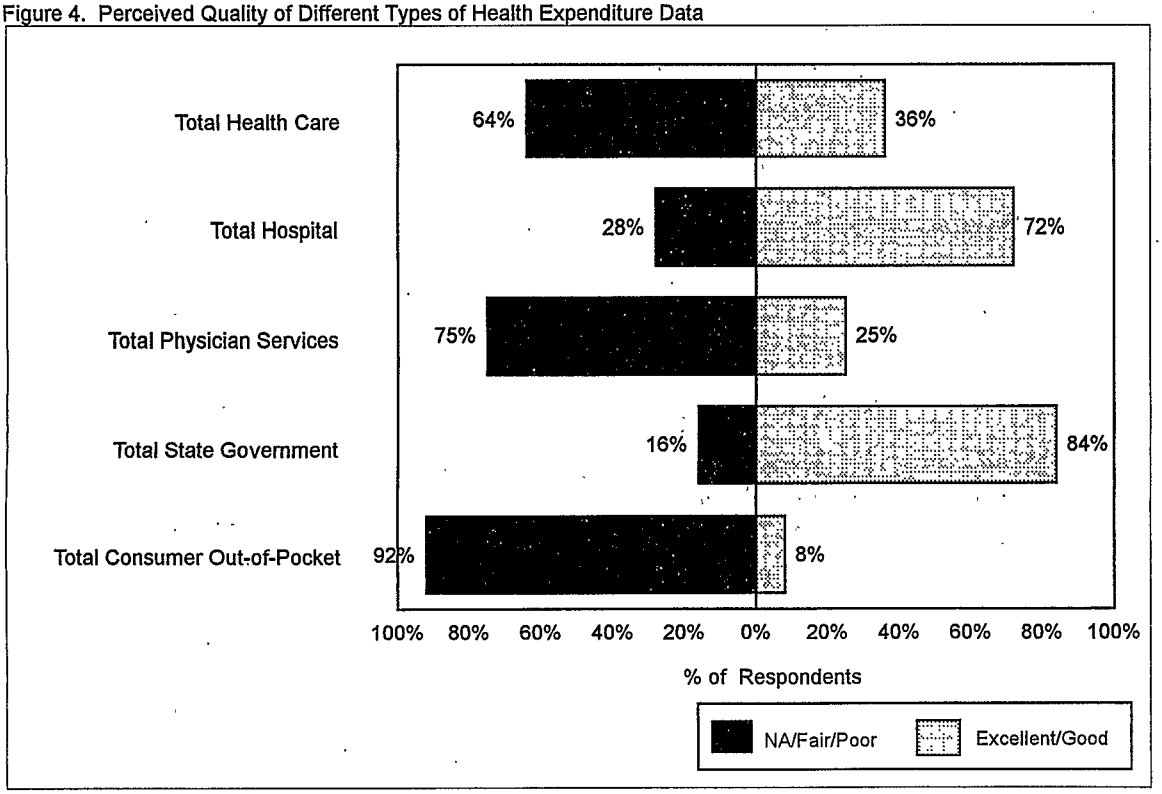
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.
NOTE: Other categories were not very or not at all confident.

Figure 3. Perceived Quality of Different Types of Insurance Coverage Data



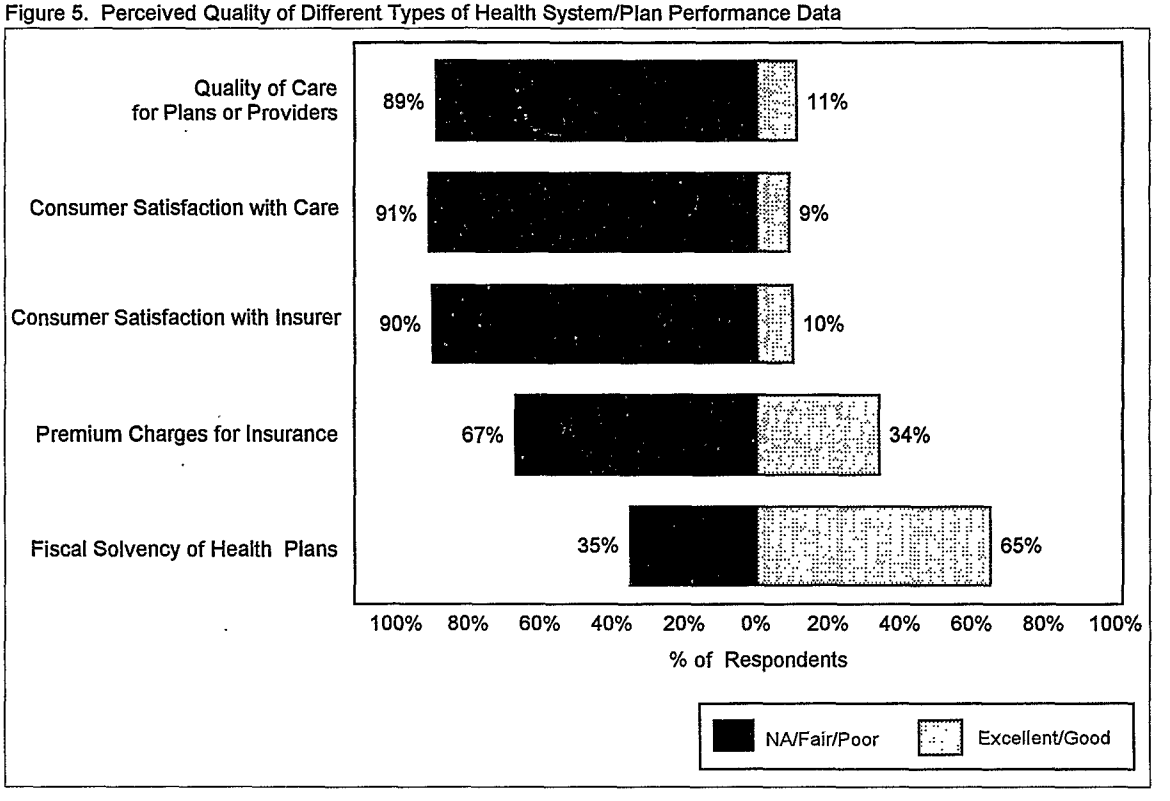
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.
NOTE: NA = Not available.

Figure 4. Perceived Quality of Different Types of Health Expenditure Data



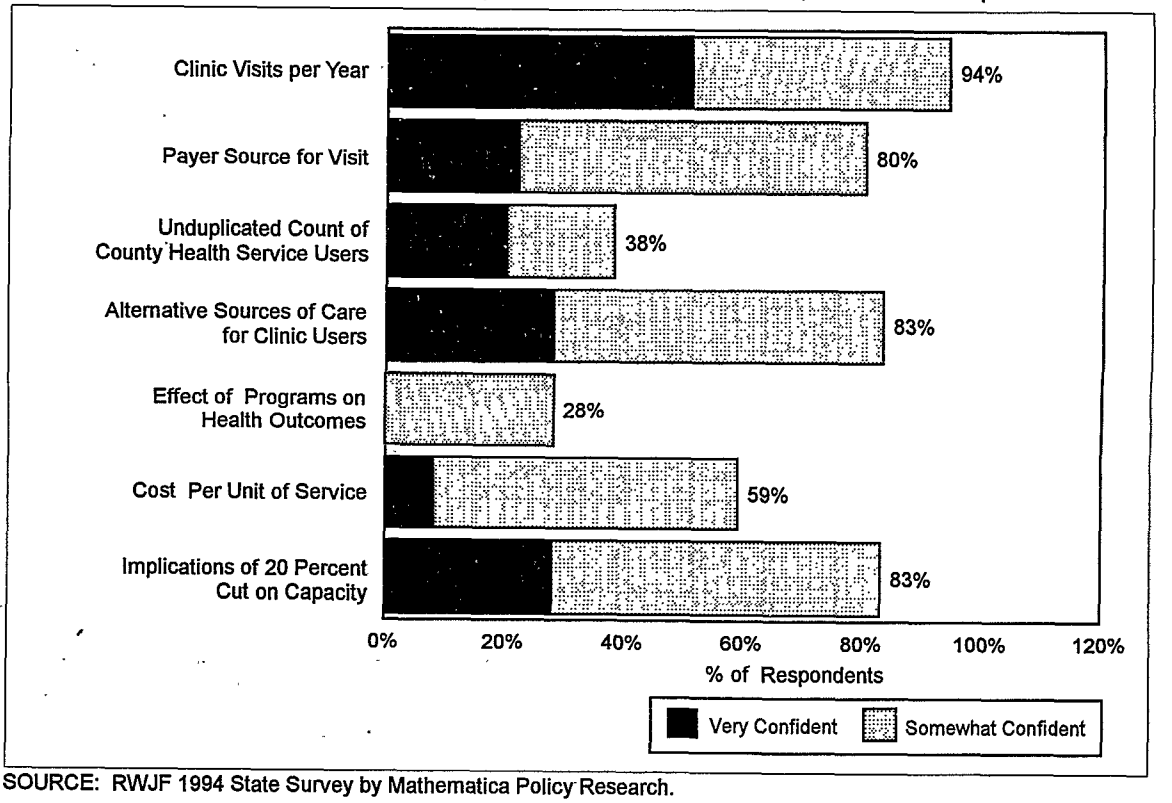
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.
NOTE: NA = Not available.

Figure 5. Perceived Quality of Different Types of Health System/Plan Performance Data



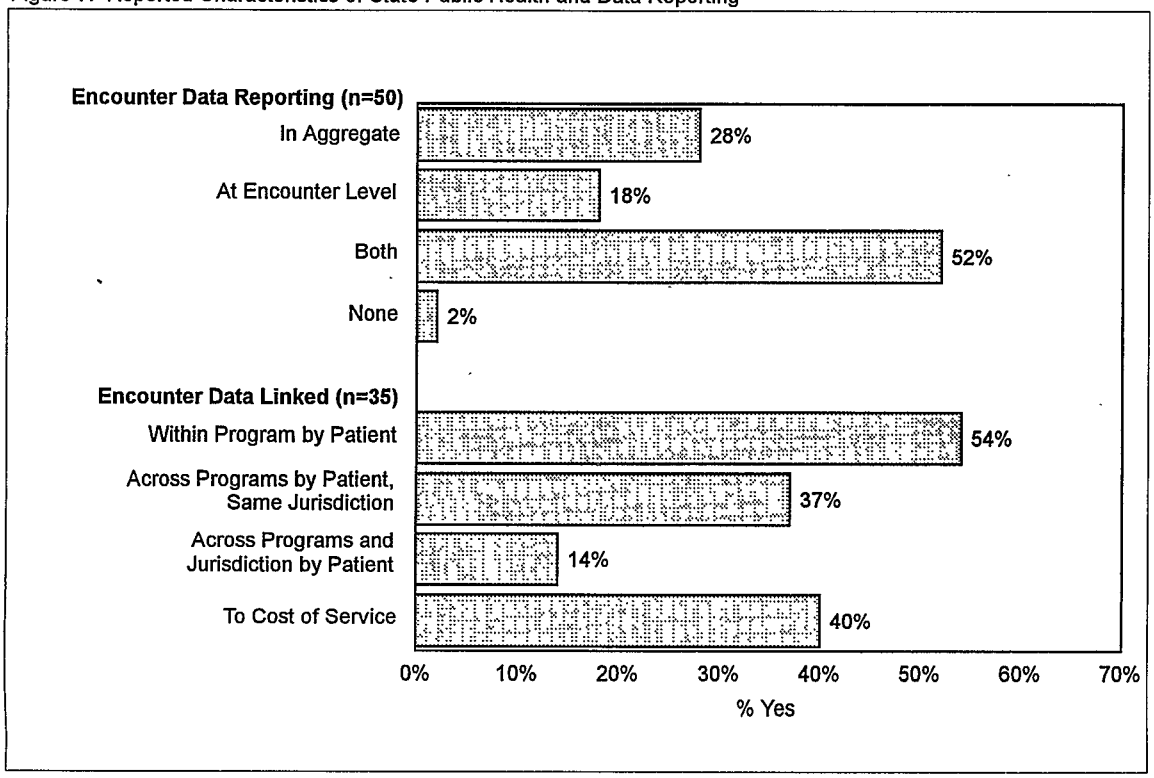
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.
NOTE: NA = Not available.

Figure 6. Confidence in Health Data to Provide Specified Public Health Information, Public Health Respondents



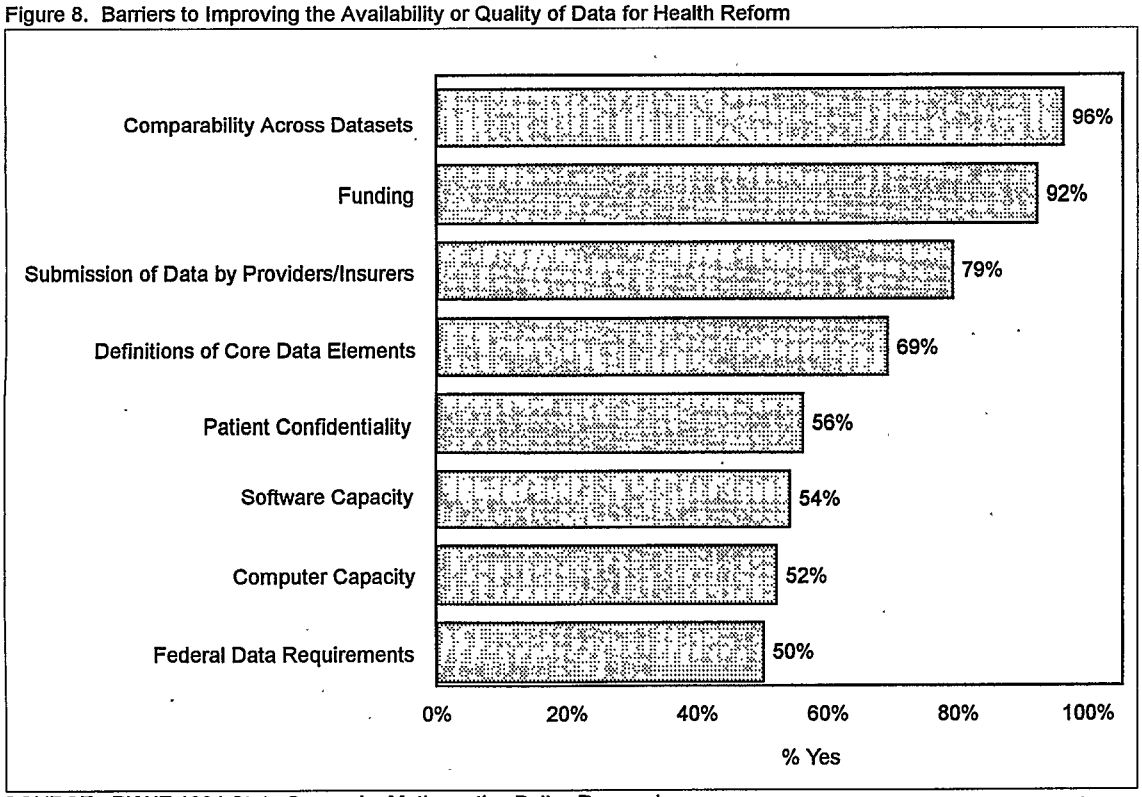
SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.

Figure 7. Reported Characteristics of State Public Health and Data Reporting



SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.

Figure 8. Barriers to Improving the Availability or Quality of Data for Health Reform



SOURCE: RWJF 1994 State Survey by Mathematica Policy Research.

MONITORING ACCESS IN STATES WITH MEDICAID WAIVERS: ROLE OF THE BUREAU OF PRIMARY HEALTH CARE

Richard C. Lee, Bonnie Lefkowitz
Bureau of Primary Health Care

Introduction

Many States are setting up Health Care Reform plans through the medium of Medicaid waiver demonstration projects. The declared objectives of these projects are to improve access for Medicaid-eligibles and uninsured persons while simultaneously reducing the costs of providing this care. The Health Care Financing Administration (HCFA), because of its responsibility for the Medicaid program, is responsible for approving and monitoring these waiver projects.

Medically underserved populations in every State, including both Medicaid recipients and other low-income uninsured persons, are currently being served through a variety of programs funded by the Bureau of Primary Health Care (BPHC) under the Public Health Service Act. These vulnerable populations are also served by other Federally Qualified Health Centers (FQHCs), typically run by State or local health departments or community groups, which have been identified by BPHC as providers of primary care services to underserved persons and which "look like" (i.e. meet the same requirements as) the BPHC-funded programs. (The term FQHCs is defined to include both BPHC-funded projects and "look-alikes".)

By using FQHCs, many previously unserved or underserved patients have achieved access to continuous, quality primary health care at relatively low cost to taxpayers. Therefore, BPHC and HCFA have mutual concerns that the State Medicaid waiver plans are implemented in such a way as to assure continued access to quality health care for these patients.

One way that these concerns have been addressed has been by HCFA's including, in the "Terms and Conditions" of many of the waivers it has issued, a requirement that "the State shall require managed care organizations (MCOs) to contract with FQHCs unless the MCO demonstrates that both adequate capacity and appropriate facilities for vulnerable populations exist in its area without the use of FQHCs." The Terms and Conditions have also frequently included Access Standards, including a requirement that the location where a patient will receive services should be within 30 miles or 30 minutes of the patient's residence. In addition, most of the Terms and Conditions require the State to monitor the number and types of providers before and after the waiver, and various measures of recipient access to services, including waiting times.

However, data are needed in order to make an informed review of waiver proposals and of implementation plans addressing the general issue of assuring access to vulnerable populations and/or the more specific FQHC issue, as well as to monitor the plans when implemented. These may include data on the location of vulnerable populations, data on indicators of their access to primary health care, and data on the location of existing FQHCs. BPHC has an extensive data base on variables relevant to these issues, and is making such data available to HCFA for use in both analyzing waiver requests and monitoring access in States where waiver plans have been implemented.

BPHC Programs for Vulnerable Populations

BPHC is responsible for six major programs targeted at underserved areas and populations. They are:
(1) Community Health Centers (CHCs);
(2) Migrant Health Centers;
(3) Public Housing Clinics;
(4) the National Health Service Corps;
(5) Health Care for the Homeless; and
(6) Ryan White Title 3B HIV projects.
These programs involve 2500 total sites providing 9 million people with comprehensive preventive and primary care, case management of specialty and inpatient services, and various enabling and facilitating services.

These centers/sites have the potential of making a major contribution to Medicaid managed care. They already serve 4 million Medicaid beneficiaries, together with many uninsured persons. They are the only source of care in many areas. Many already participate in managed care through Integrated Service Networks supported or encouraged by BPHC. As of December 31, 1994, 157 CHCs were prepaid plan providers, with a total enrollment of 566,076. Studies[1,2,3] indicate that these projects provide effective and efficient primary care, and that their services to Medicaid-eligible users are less costly when

compared with care obtained by Medicaid-eligibles in the same service areas who are non-users (or only occasional users) of CHCs.[4]

BPHC Data Bases and Data Collection Activities

BPHC has a variety of databases which contain information relevant to assessing and monitoring access of vulnerable populations to primary health care. These include both databases on the projects it funds and databases relevant to assessment of areas' and population groups' needs for and access to primary medical care. There are also data collection activities now in progress which will allow analysis on a sample of projects. These databases and data collection activities include:

(1) The Bureau Common Reporting Requirement (BCRR) database, maintained by BPHC and its predecessor Bureaus since the 1970s. This database contains, for each project or connected group of projects, information on the staff and resources available, volume of services provided, and number of users.

BPHC's new Uniform Data System (UDS) reporting system, effective January 1996, will add demographics of the user population, crosswalk to the HCFA Medicare/Medicaid reporting system, and data on selected diagnoses.

(2) BPHC has worked with NCHS to design and conduct user/visit surveys of health centers on the Health Interview Survey (HIS) and NHAMCES models, in order to study access, diagnoses, services, continuity, satisfaction, and outcomes in the CHC environment. The results of those surveys are forthcoming. A current project will adapt these user/visit surveys for waiver States.

(3) BPHC assists each grantee with clinical self-evaluation measures corresponding to HEDIS quality standards.

(4) The Health Professional Shortage Area (HPSA) database. HPSAs are areas, population groups and facilities which have been determined to have shortages of health professionals, and are therefore eligible to apply for placement of National Health Service Corps (NHSC) personnel. The HPSA database contains data on every county and every designated HPSA in the United States, including the definition of each service area in terms of counties, census tracts or census divisions; population of each area or population group; number of full-time-equivalent (FTE) primary care physicians serving the HPSA; ratio of population to FTE primary care physicians, poverty rate, and other variables. For all designated HPSAs, the database also contains the estimated travel time and distance to the nearest source of care outside the HPSA. County-level data on infant mortality rate and rate of low birthweight births are also included. Each HPSA is required to be updated every three years to remain designated.

(5) The Medically Underserved Area/Population (MUA/P) database. MUAs are areas which have been designated as having a shortage of primary care services based on their scores on the four-variable Index of Medical Underservice (IMU); MUPs are population groups designated as having such a shortage either based on an IMU score or a Governor's recommendation. Areas and populations designated as MUA/Ps are eligible to apply for CHC funding. This database identifies each designated MUA or MUP and its IMU score or status as a Governor's request.

BPHC is currently developing a new method of designation to replace both the HPSA and MUA/P systems with one self-consistent system. It would include many of the same variables now used in HPSA and/or MUA designation, and others as well.

(6) The BPHC "Geofile", containing census demographic data for all counties, census tracts and census divisions; AMA/AOA physician data by county; NCHS mortality and natality data by county; and other variables.

(7) BPHC has, through Cooperative Agreements with all the States, stimulated the development and submission of State Primary Care Access Plans, which contain information on the number of primary care providers and the unmet need for primary care providers, by county (and for subcounty service areas if defined by the State). We are currently assembling a database from this data, and plan to link it to the other databases identified above.

Schematic for Access Indicators

Below is a schematic of BPHC's anticipated efforts in monitoring access in waiver States.

In the baseline, we examine the gaps in provider capacity within the areas the State has agreed (through the designation process) are underserved. This would include examining the extent to which these gaps are currently being filled through Federal interventions such as NHSC providers, CHCs, or other FQHCs.

Through the Primary Care Access Plan process and through the review of implementation plans submitted in the

context of waiver requests, the States are queried as to how they intend to assure adequate capacity, and what role Federal interventions will play.

In the coming months, BPHC will assemble baseline data from the HPSA/Geofile databases for the 12 or more currently-approved waiver States, as well as for those with waiver applications under review by HCFA. To this will be added data on CHCs and FQHCs from the BCRR database and other sources, and data from the Primary Care Access Plans.

This baseline information is available for structure and process elements currently.

SCHEMATIC FOR ACCESS INDICATORS

	Baseline	Annual Updates	3- to 5-year Updates
Structure/ Inputs	Provider capacity Distance Travel time Physical plant Enabling staff	Provider-specific and some areawide	Areawide
Process/ Utilization	Waiting time Appointment time User-visit rates Satisfaction Costs	Provider-specific	Areawide survey
Intermediate Outcomes	Immunization rates Screening rates Chronic disease control	Provider-specific	Areawide survey
Health Status	Infant mortality Low birthweight ACS conditions	Provider-specific	Areawide; include age-adjusted mortality by demographic groups

Next Steps

In the future, BPHC will work to deepen the baseline information, adding elements on intermediate outcomes and health status from the User/Visit Survey and other evaluation projects.

In addition, updates will also be scheduled, and compared with the baseline, first on a provider-specific basis and then also on an areawide basis as new information becomes available from the Primary Care Access Plan and designation databases.

Updates of outcome and health status information will similarly be available first for BPHC-funded providers and then, as surveys are adapted for wider use, for areas as well.

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[2]Stuart, Mary and Steinwachs, Donald, "Patient-Mix Differentials Among Ambulatory Providers and Their Effects on Utilization and Payments for Maryland Medicaid Users." Medical Care, Vol. 31, No. 12: 1119-1137.

[3]Lewin-VHI, Inc. and MDS Associates, "Community Health Centers' Performance Under Managed Care: Executive Summary." PHS-HRSA-BPHC Report, December 1994.

[4]Rodgers, Judy, Duggar, Ben, et al., "Utilization and Cost of Medicaid Services Provided to Users and Non-Users of Community Health Centers," publication forthcoming.

MONITORING ACCESS TO HEALTH CARE AT THE COMMUNITY LEVEL

Jeannette Jackson-Thompson, Missouri Department of Health
Bernard Ewigman and Robin Kruse

Introduction

Access to health care can be defined as the ability to obtain appropriate health care when it is needed. Access "implies that people have a place to go and the financial and other means of obtaining care."[1(p.180)] Many people in this country do not have a place to go and are unable to obtain health services they need, either because of the high cost of needed services or the lack of service availability in their geographic area. People without easy access may delay seeking care; they may face barriers that delay access to care; and they may use the emergency room (ER) as a primary care substitute. Long delays in seeking and/or accessing primary care and inappropriate ER use lead to lowered health status for individuals and place an increased burden on some providers.

The Missouri Department of Health (MDOH) has established as one of eight strategic goals for the year 2000 a goal of universal access:

> By 2000 quality preventive, primary, acute and rehabilitative care will be universally available and accessible to all Missourians.[2(p.21)]

MDOH is especially concerned with lack of access to preventive and primary care, the effective use of which should ease some of the personal and financial burdens of acute care.[2] To measure access at the state level, MDOH added a four-question, state-developed module on access to care to its 1990 Behavioral Risk Factor Surveillance System (BRFSS) questionnaire. The same module was also used in two special local area surveys conducted by MDOH in 1990.[3] Regional differences were observed in access. For example, 9.6% of BRFSS respondents statewide reported they had no form of health insurance, compared with 13.5% of respondents in one six-county area and 16.0% of respondents in eight inner-city neighborhoods.[4]

To plan effectively for adequate health services so that timely and appropriate care is available to all who need it, local level information on utilization patterns, access to health care and barriers to care is needed. Such information is frequently lacking.

In 1992, health care planners and providers had no clear understanding of how many residents of Boone County, Missouri, had problems getting needed health care or the barriers which prevented residents from accessing the health care system. Despite an apparent abundance of physicians and hospital beds in the county, providers in the community believed that many Boone County residents were unable to access and receive appropriate health care in a timely fashion. Their belief led to the establishment of a new clinic, the Boone County Family Health Center (now the Family Health Center at Parkade), which serves uninsured and underinsured Boone County families and individuals. The lack of knowledge about access and barriers plus the presence of the clinic provided the impetus for the research reported here, a population-based survey of Boone County adults.

This project, a collaborative effort involving both public and private partners, was undertaken to assess current health needs in the community, particularly of low-income and underinsured residents, and provide a baseline for measuring progress toward the goal of universal access to basic health care. MDOH conducted random-digit-dialed (RDD) telephone interviews with 897 adult (≥ 18 years of age) residents of Boone County, Missouri during October 1992. The study was funded by Preferred Health Plans of Missouri. The survey instrument, developed by MDOH, the Family Health Center at Parkade and the City of Columbia/Boone County Health Department, included questions from the 1992 Missouri BRFSS questionnaire plus additional questions on access, utilization, need and perceived barriers to care. Results have been used to determine the prevalence of specific barriers to health care access and the populations most affected by these barriers. The survey is also being used to develop a model for continued measurement of health care access, utilization and need as managed care becomes more prevalent in Missouri.

Methods

The specific aims of the study were 1) to determine the prevalence of adult county residents experiencing barriers to health care by type of barrier and 2) to characterize the populations experiencing barriers. The study was based on BRFSS methods and techniques.[11,12] A simple random sampling frame was used rather than the modified Waksberg cluster sampling used for Missouri BRFSS data collection.[3] Starting with a list of all residential telephone prefixes known to be in use in Boone County, MDOH staff generated 10,000 random telephone numbers. Two prefixes assigned to the University of Missouri-Columbia (UMC) were not included among residential prefixes, thus excluding all UMC students living in university housing. These students had access to an on-site student health clinic and could be referred to UMC Hospital and Clinics through a mandatory campus health care plan. Full-time students living off-campus were included in the survey sample but were excluded from most analyses for the same reason.

Data Collection. Interviews were conducted during October 1992 by trained interviewers. A two-stage, RDD technique was used. During the first stage, most nonworking and ineligible telephone numbers were eliminated. In the second stage, a respondent was identified from among all adult residents of a household. A state-developed, menu-driven CATI (computer-assisted telephone interviewing) system loaded on stand-alone personal computers (PCs) was used for data collection.[3] Calls were made weekdays, evenings and weekends. Up to twenty attempts (four attempts over five different calling periods) were made to reach each RDD number. Only one respondent in each household was eligible for inclusion in the study.

Successful contacts that resulted in 897 completed interviews were made with 1,055 eligible households (defined as a private residence in Boone County with at least one person 18 years of age or older living in the household), for a completion rate of 85%. Of the remaining 158 residential numbers, 133 potential respondents refused to participate. Another 25 respondents were unavailable during the survey period, started but did not complete an interview or were ineligible for inclusion in the study due to age (< 18) or selection procedure (wrong household member selected).

Survey Instrument. The survey instrument contained 77 questions and was a modified version of the 1992 Missouri BRFSS questionnaire. Twenty-six percent of the questions were developed or adapted from non-BRFSS sources for this survey; 64% were core BRFSS questions and 10% were state-added BRFSS questions already in use. MDOH and University of Missouri-Columbia faculty and staff analyzed data.

Key Questions on Barriers to Health Care. Three questions were used to determine if the respondent actually experienced one or more barriers to health care (table 1). Respondents were asked if they had a doctor (or other type of provider) who they saw for regular health care, if they had any kind of health insurance or health care plan and if there was a time during the last 12 months when they needed to see a doctor but could not for any of the following reasons: cost, lack of transportation, couldn't get appointment, doctor wouldn't accept Medicaid/Medicare, limited hours and/or days service is available or another reason they could specify. The first two questions had been used on Missouri BRFSS and earlier special survey instruments and the third question was developed for this survey.

Table 1. Determination of Barriers to Health Care Access

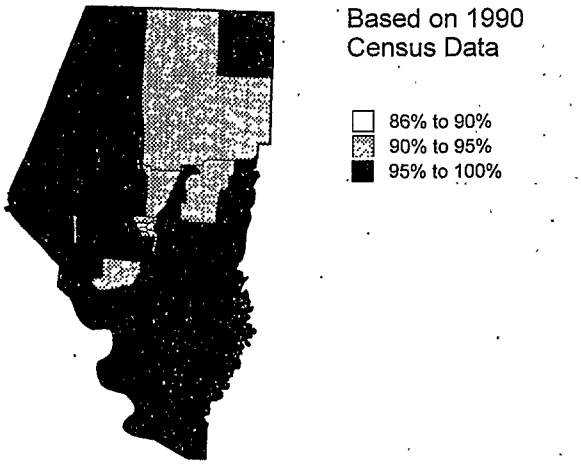
- Do you have a doctor who you see for regular health care?
- Do you have any kind of health insurance or health care plan?
- Was there a time during the last 12 months when you needed to see a doctor but could not for any of the following reasons?
  - Cost
  - Lack of transportation
  - Couldn't get an appointment
  - Couldn't find a provider to accept Medicaid/Medicare
  - Limited hours of services availability
  - Other (specify)

Analysis. Simple frequencies were calculated by sociodemographic groupings using SAS.[13,14] Projections for number of residents impacted were based on 1990 census data for Boone County.

Study Area. Boone County is located in the center of Missouri, midway between St. Louis and Kansas City. The county has a mixed economy, based primarily on health care, institutions of higher education, corporate regional offices, light industry and farming. The 1990 population of Boone County was 112,379.[5]

Boone County is experiencing more rapid growth than the state as a whole; the 1994 population estimate was 121,500.[6] Projections to the year 2000 indicate a 10 year population growth of over 17%, compared with a 4.2% gain for Missouri overall.[7] The largest city is Columbia, with a 1992 population of 73,000. In 1992, there were seven other incorporated municipalities in the county, with populations ranging from under 200 to over 3,500, and a number of unincorporated hamlets. Over 95% of Boone County households had at least one residential telephone in 1990 (map 1).[7]

Map 1. Percent Telephone Coverage Boone Co., MO



According to MDOH, Boone County has 36.3 full-time physician FTEs per 10,000 population, while the state of Missouri has 16.2 full-time physician FTEs per 10,000 population.[8] The American Medical Association reports 19.8 patient-care physicians per 10,000 population in the United States.[9] Using 1990 census data[5] and figures published by the American Hospital Association,[10] Boone County has 142 hospital beds per 10,000 population, while Missouri and the United States have 55.8 and 47.7 beds per 10,000 population, respectively.

Results

The 897 survey respondents and the county population, based on 1990 census data, were similar with respect to age, income and household composition (table 2). African Americans and other non-whites constituted 7.5% and 3.5%, respectively, of the county population but only 5.2% and 3.0%, respectively, of the survey sample. Survey respondents were more likely to be female (58.9% v. 51.6%), college educated (41.7% v. 36.5%) and not in the work force (36.6% v. 26.3%) than the county population and less likely to be employed (58.2% v. 65.9%), disabled (1.9% v. 4.6%) or have less than a high school education (8.8% v. 15.2%). Full-time students (129) were removed from subsequent analyses, leaving a final sample of 768 Boone County residents.

Table 2. Characteristics of Sample (n=897) and Boone County Population

			Percent Composition	
			County	Survey
◆	Race	White	89.0	91.5
		Black	7.5	5.2
		Other	3.5	3.0
◆	Age	18-24	24.1	21.9
		25-44	45.4	42.8
		45-64	19.0	20.0
		65+	11.5	14.7
◆	Income	<$10,000	18.6	21.5
		$10,000-$19,999	20.7	19.0
		$20,000-$49,999	41.5	41.8
		>$50,000	19.2	17.7
◆	Education*	Less than high school	15.2	8.8
		High school/GED	25.3	27.5
		Some college	23.0	21.8
		College or higher	36.5	41.7
◆	Sex	Male	48.4	41.1
		Female	51.6	58.9
◆	Employment	Employed	65.9	58.2
		Unemployed	3.2	3.2
		Disabled	4.6	1.9
		Not in work force	26.3	36.6
◆	Household composition	Married couple w/ kids	24.3	24.6
		Married couple no kids	25.5	25.1
		Male parent w/ kids	1.5	1.7
		Female parent w/ kids	6.5	6.2
		Other	42.2	42.4

*Respondents and residents age 25 or more for educational level.

Measurements of barriers to care can be categorized as financial, temporal or provider-related. Financial variables include insurance status and problems with the cost of care. Variables used to assess temporal barriers to care include appointment availability and limited hours. Provider-related issues include lack of access to a regular provider, providers who refuse to accept Medicaid or Medicare and distance or lack of transportation to a provider.

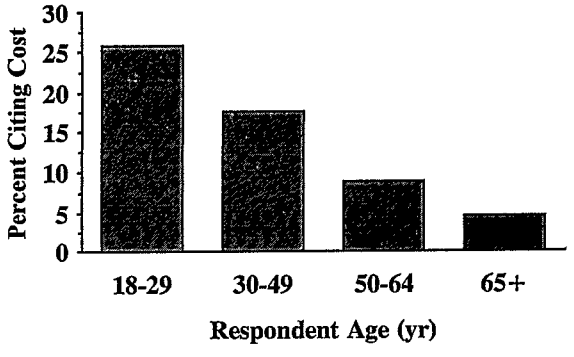
Fifty-two percent of respondents reported experiencing one or more barriers to health care during the preceding 12 months. Projecting to the adult population of Boone County, nearly 43,000 adults would have experienced at least one barrier to health care during the period. Table 3 shows the breakdown by specific variables. The first column indicates the percent of respondents reporting a particular barrier. The middle column represents the proportion of these respondents who could not obtain medical care when they needed it for any reason during the previous 12 months. Multiplying column one by column two yields the percent of respondents reporting a particular barrier who were unable to obtain care during the preceding year. For example, the most frequently reported barrier was having no regular provider, reported by 34% of respondents. However, only 38% of respondents with no regular provider reported problems getting care when it was needed, leaving 13% of respondents without a regular provider who were unable to get care when they needed it.

Table 3. Prevalence of Barriers to Health Care Among Respondents

	Percent Reporting Barrier	Percent Lacking Care	Percent Affected
Financial barriers			
◆ Cost	16	100	16
◆ No health insurance	13	62	8
Temporal barriers			
◆ Appointment availability	11	100	11
◆ Limited service hours	11	100	11
Provider-related barriers			
◆ No regular provider	34	38	13
◆ Transportation	4	100	4
◆ No Medicare/Medicaid	3	100	3

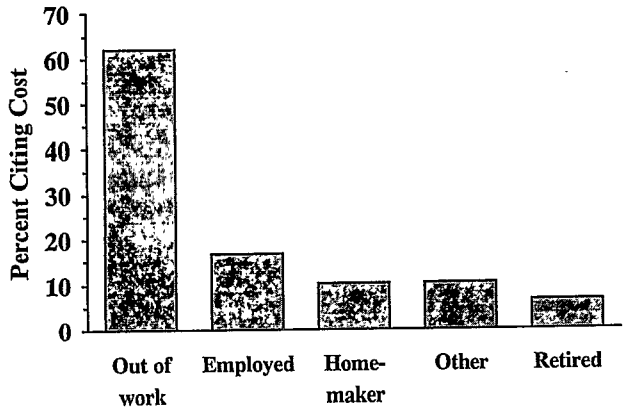
Cost was the second most common barrier, reported by 16% of respondents, including 31% of those with household incomes below the federal poverty level, 24% of the "near poor" (100-200% of poverty) and 5% of those with incomes at least twice the federal poverty level. All respondents who reported cost as a barrier were prevented from getting medical care when they needed it at least once during the preceding 12 months. Thus, the percent actually affected by cost remains 16%, making it the most prevalent barrier to health care for Boone County adults. Projected to the adult population of the county, 13,000 Boone County adults would have experienced cost as a barrier to getting needed care in the preceding year.

Figure 1. Boone County Adults Experiencing Cost as a Barrier, by Age



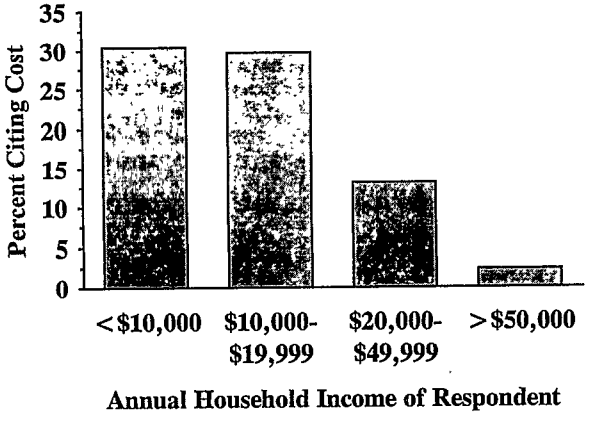
Younger adults experienced cost as a barrier to a greater degree than older adults (figure 1). Of individuals who were out of work, nearly 62% experienced cost as a barrier (figure 2).

Figure 2. Boone County Adults Experiencing Cost as a Barrier, by Occupation



Notably, approximately 17% of employed respondents also experienced cost as a barrier. As might be expected, the percent of adults experiencing barriers to health care increased as household income decreased and was highest for respondents

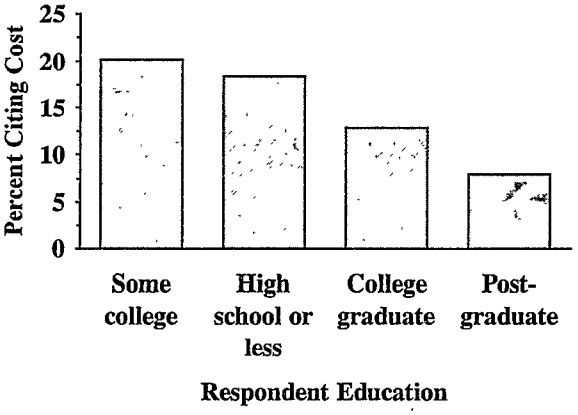
Figure 3. Boone County Adults Experiencing Cost as a Barrier, by Household Income



with annual household incomes below $20,000 (figure 3). As educational attainment increased, the importance of cost as a barrier decreased (figure 4).

The population subgroups reporting the greatest difficulty with cost in absolute numbers are white, employed and/or adults aged 18 to 49 (table 4). Groups disproportionately

Figure 4. Boone County Adults Experiencing Cost as a Barrier, by Education*



***Respondent age 25 years or more.**

affected by the cost of medical care include African Americans and unemployed persons. Population subgroups reporting the greatest difficulty with cost in terms of both proportions and absolute numbers are respondents with annual household incomes under $20,000, those who have children under 18 years of age and those who have not graduated from college.

The third most common barrier was lack of health insurance, reported by 13% of respondents (table 3). Of uninsured residents, 39% had been without coverage for at least one year and 23%, for over five years.

Table 4. Characteristics of Boone County Adults Experiencing Cost as a Barrier to Health Care

	Survey % Affected	County Projection
◆ Race		
◆ Caucasian	15	11,000
◆ African-American	25	1,360
◆ Employment		
◆ Employed	17	9,000
◆ Unemployed	62	1,900
◆ Age		
◆ 18-49 years old	21	12,500
◆ >49	7	1,380
◆ Annual income		
◆ <$20,000/yr	30	5,000
◆ $20,000 or more	10	2,500
◆ Household composition		
◆ Family with children	21	2,800
◆ Family without children	13	1,500
◆ Education (age 25 or more)		
◆ Not a college graduate	19	7,600
◆ College graduate	11	2,460

Appointment availability and limited hours of service were each reported as barriers by 11% of respondents (table 3). Ten percent of respondents who used the ER reported they did so because they had no other place to go or could not get an appointment with their usual provider. Respondents with household incomes < $20,000 were over twice as likely to have visited the ER three or more times than those with incomes ≥ $20,000 (5.4% and 12.9%, respectively).

Discussion

Access to health care is a major problem in Boone County, affecting over half of all adults. In terms of actually preventing individuals and families from getting care when it is needed, cost is the most prevalent barrier to health care access, affecting 16% of respondents in the past year. Some population subgroups are disproportionately affected by the cost of health care; these include African Americans, unemployed persons, young families with children and respondents with lower household incomes. Parallel to the above finding, a disproportionate chronic disease morbidity and mortality burden is shared by these same population subgroups.[1,15,16,17] These two findings may be related. Previous research has identified that part of the disproportionate burden can be attributed to lack of access to appropriate and timely health care.[1,15,16,18,19]

This study has a number of strengths. It is a population-based study focusing on a single county. Existing standardized questions were supplemented with locally-developed or adapted questions. Interviewers were trained and experienced in collecting behavioral risk factor data. An excellent response rate was achieved. Study results provide a good basis for health care planning at the local level.

The study also has a few weaknesses. County residents without a telephone were ineligible for inclusion; however, less than 5% of households in the county had no telephone. Access and barriers were self-reported and were based in part on responses to newly developed questions that had been tested and piloted but had not undergone extensive testing for validity or reliability. In two published studies that have attempted to measure validity,[20,21] substantial agreement was shown for most cardiovascular risk factors between BRFSS-system collected data and physiologic/in-person interview data. Two other studies, one conducted in New York City and one by MDOH BRFSS staff, have measured reliability.[22,23] The findings of the two studies generally agree; in items comparable between the New York study and the Missouri study, the Missouri estimates of reliability were slightly higher.[23] The Missouri study found no clear pattern in reliability based on whether BRFSS questions were developed at CDC or in Missouri. Missouri results indicate that reliability may be higher for behavioral variables and lower for knowledge and attitudinal variables.[23] All three key questions used to measure access to care related to behaviors rather than knowledge or attitudes. African Americans, particularly African American males, were under-represented in the sample, as were individuals with less than a high school education. Nevertheless, we were able to identify differences by socioeconomic and ethnic groups despite this weakness. In addition, the purpose of our research was not solely to estimate barriers to access among minorities but to give a good representation to the county as a whole.

Since relatively few population-based local-level studies focusing on access to health care have been reported, this study can provide some useful insights to other researchers. As managed care comes to mid-Missouri, this study can provide baseline data and serve as a model for continued measurement of access to care, utilization and need.

Acknowledgments

We are grateful to supervisors and surveyors from Manpower, Inc., and in particular to Jane Heath, Anna Klick and Carol McClanahan, who supervised data collection. We also thank the following: Eduardo Simoes, for helpful comments on the manuscript, Theo Murayi, Marty Maas and Roslyn Williams, for assistance in this project, MDOH Division of Chronic Disease Prevention and Control; and Bill Elder and Tanna Klein, for technical assistance, Office of Social and Economic Data Analysis, UM-C. Thanks are also due to four individuals who were instrumental in conceptualizing this project: Ross C. Brownson, Coleen Kivlahan, Jane Kruse, Michael R. Sanford, Linda Sancik and Nancy Sublette.

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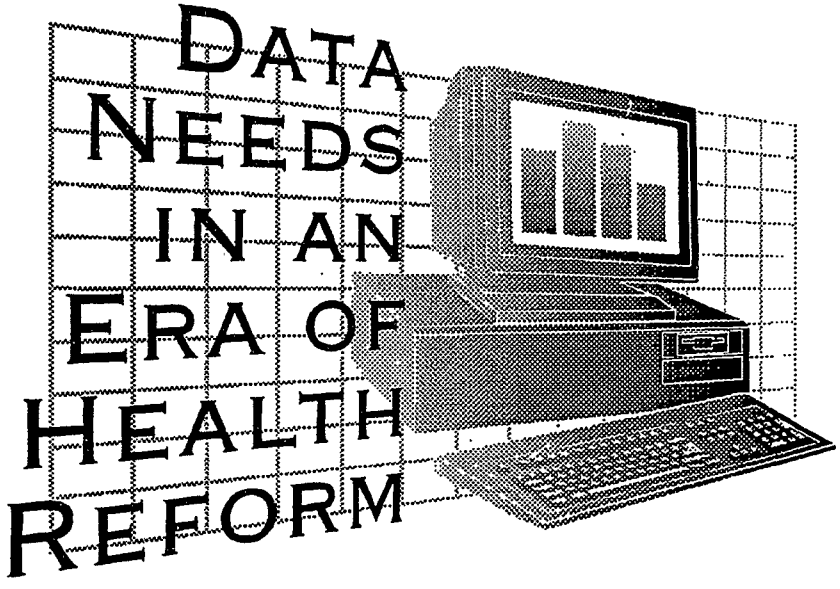
Session Q

Prevention Stategies



U.S. PREVENTIVE SERVICES TASK FORCE RECOMMENDATIONS FOR VULNERABLE POPULATIONS

Carolyn DiGuiseppi
Agency for Health Care Policy and Research

Paper not available for publication.

VARIATIONS IN WELL-CHILD VISIT RATES BY MEDICAID ELIGIBILITY STATUS

Elicia J. Herz, The MEDSTAT Group,
Norma I. Gavin and Kate Sredl

Study Objective and Background

Under a three-year HCFA-funded project, the MEDSTAT Group is investigating the impact of OBRA-89 legislative changes on the provision of preventive and curative services to Medicaid children both within and outside State EPSDT programs. By fiscal year 1995, all States are expected to increase participation in EPSDT to 80 percent of all children enrolled in Medicaid.

Overall baseline analyses of 1989 data indicate that only 41 to 51 percent of Medicaid children recommended to have well-child visits did so, and only 30 to 44 percent of recommended visits were made. Medicaid children as a whole were receiving well-child care at rates only slightly lower than children with private health insurance.

The objective of the analyses described in this report was to investigate variations in the receipt of well-child visits among Medicaid children by eligibility category. Medicaid children in different eligibility categories vary in many respects, including for example, age distribution, Medicaid enrollment duration, health status, financial resources and EPSDT outreach activities. These characteristics may influence parents' decisions to seek health care for their offspring and thus receipt of services such as well-child visits. Results from these analyses will help target new policy and programmatic initiatives to the groups of children with the greatest need for preventive services.

Methodology

The EPSDT participant and screening ratios reported to HCFA by the States in 1989 were not computed in a consistent manner, nor were they believed to provide accurate measures of States' success in reaching and screening Medicaid children. In particular, the ratios neglected to take the periodicity schedule for screening visits relevant to the child's age and length of Medicaid enrollment into consideration and counted children in continuing care arrangements as having received all screens whether or not they actually did so.

To overcome these measurement problems, we developed new methods to more accurately assess the receipt of Medicaid-financed well-child services rendered both within and outside formal EPSDT programs. To do so, we assigned two weights to each child in the database—a participation weight and a compliance weight. The participation weight ($\bar{P}$) reflects the child's expected probability of being a user of preventive care visits during the year while the compliance weight ($\bar{S}$) reflects the child's expected number of preventive care visits during the analysis year. We adjusted the values assigned for both weights for the child's age and enrollment duration and the American Academy of Pediatrics (AAP) screening periodicity schedule.

In deriving the weights, we first determined the recommended number of screening visits for a child enrolled for the full 12 months of 1989 based on the 1989 AAP periodicity schedule and the age of the child at the end of the year. For younger children, the recommended number of screening visits was determined for each month of age. For children in age groups for which only one screening visit was recommended every other year, the child was assumed to be equally likely to have the screening visit anytime during the two years. Therefore, the recommended number of screening visits was one-half (0.5) visit; that is, the probability of an event occurring in either of two periods under a uniform distribution function over the two periods.

We then adjusted for duration of enrollment by multiplying the number of recommended screening visits by the fraction of the year that the child was enrolled, or if the child was less than 12 months of age, the fraction of the child's life during which s/he was enrolled. This methodology assumes that a child was equally likely to receive a screening visit during a month in which s/he was enrolled as during a month in which s/he was not enrolled. Thus, the expected number of screening visits, $\bar{S}_{ij}$, for the ith child in the jth age group is:

$$\bar{S}_{ij} = \frac{\text{Months Enrolled}_{ij}}{\text{Months of Life}_{ij}} \times \text{No. of Recommended Visits}_{j}$$

where months of $life_{ij}$ is 12 for all children except infants. The child's compliance weight is simply the expected number of screening visits, $\bar{S}_{ij}$. The participation weight, the probability of the child being a user of preventive care visits, is equal to one if the expected number of screening visits for the child is greater than or equal to one. Otherwise, the child's participation weight is equal to $\bar{S}_{ij}$, that is:

$$\text{If } \bar{S}_{ij} \geq 1 \text{ then } \bar{P}_{ij} = 1;$$

$$\text{else } \bar{P}_{ij} = \bar{S}_{ij}.$$

We used these weights to compute participation and compliance rates for children in different age groups. Participation rates give the percentages of children with at least one screening visit among those recommended (expected) to have at least one screening visit. The numerator for the participation rate is the count of individuals with any preventive care visits during the year (i.e., $P_{ij} = 1$ for children with at least one preventive care visit and zero for children with no such visits). The denominator is the total expected number of participants, computed by summing the participation weights over the child population being tabulated.

$$\text{Participation Rate} = \frac{\text{Actual No. of Participants}}{\text{Expected No. of Participants}} = \frac{\sum_{ij} P_{ij}}{\sum_{ij} \bar{P}_{ij}}$$

Compliance rates give the percentages of total recommended (expected) screening visits children in different subgroups actually had. The numerator of the compliance rate is the total number of screening visits children had during the year (i.e., S_{ij}). The denominator is the total expected number of screening visits, computed by summing children's compliance weights.

$$\text{ComplianceRate} = \frac{\text{ActualNo. of Screens}}{\text{ExpectedNo. of Screens}} = \frac{\sum_{ij} S_{ij}}{\sum_{ij} \bar{S}_{ij}}$$

Data Source and Study Population

The data used in this analysis were drawn from the 1989 Medicaid Tape-to-Tape Database which includes complete enrollment and claims information for four States—California, Georgia, Michigan and Tennessee. For each of these States, all Medicaid enrollees under the age of 21 years were included in the analysis, excluding those: (1) enrolled in capitated programs, (2) residing in institutions, and (3) with dual Medicare and Medicaid coverage. For these analyses, children were classified into one of five groups based on the eligibility category under which they were enrolled for the greatest number of months during 1989: (1) AFDC cash assistance, (2) SSI blind/disabled, (3) foster care, (4) poverty-related expansion, and (5) medically needy/other.

Results and Conclusions

Among the five eligibility categories investigated, foster care children had the highest rates of well-child visit use, while SSI blind/disabled generally had the lowest such rates. Across States, the percentage of foster care children recommended to have a visit and who actually had at least one such visit ranged from 54 to 64 percent. Similar figures for the SSI blind/disabled ranged from 26 to 34 percent (see Figure 1). In addition, foster care children had 44 to 62 percent of AAP recommended visits in 1989, compared to 29 to 37 percent among SSI blind/disabled children (see Figure 2).

The high rates of well-child visit use among foster care children may be explained in part by foster parents' contractual obligations to attend to their foster children's health care needs. The low rates among SSI blind/disabled children may be explained by the need for on-going physician care to treat/manage their disabling conditions which may preclude the receipt of separately billed, and thus identifiable, preventive visits.

To further investigate the possibility that SSI blind/disabled children may be underserved with respect to preventive services, we also compared eligibility groups on immunization compliance rates (using similar computation methods as described above for preventive care visits). This analysis was based on the assumption that physicians separately bill for administration of immunizations and therefore, that these immunizations would be found in the claims database.

The data for all children show that immunization rates for SSI blind/disabled children were lower than similar rates for other Medicaid children (see Figure 3), suggesting that in 1989, SSI blind/disabled children as a whole may have been underserved with respect to preventive services vis-a-vis other Medicaid children. For the subset of children with EPSDT visits, however, there appear to be few differences in immunization rates across eligibility groups (see Figure 4). Overall, these analyses point out the need for further investigation into the reasons why SSI blind/disabled children receive fewer preventive care services than other groups of Medicaid children and how best to provide such care to this subgroup.

Figure 1: Preventive Care Visits: Participation Rates

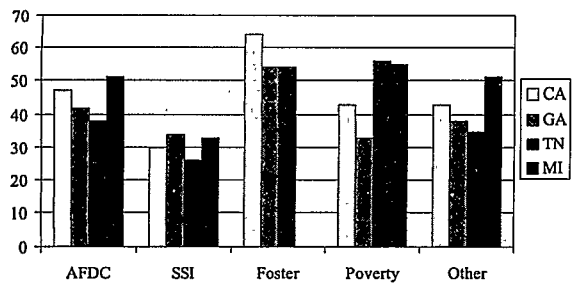


Figure 2: Preventive Care Visits: Compliance Rates

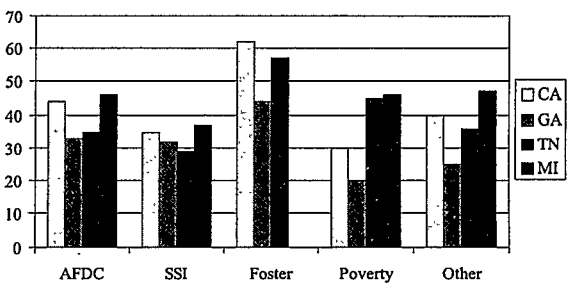


Figure 3: Age-Appropriate Immunization Compliance Rate

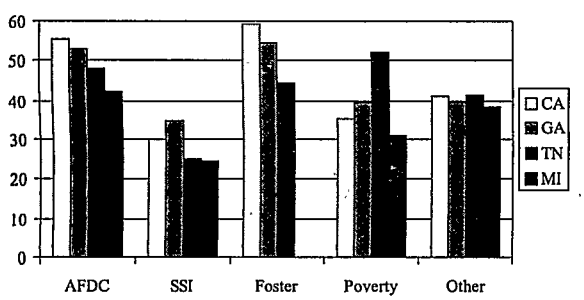
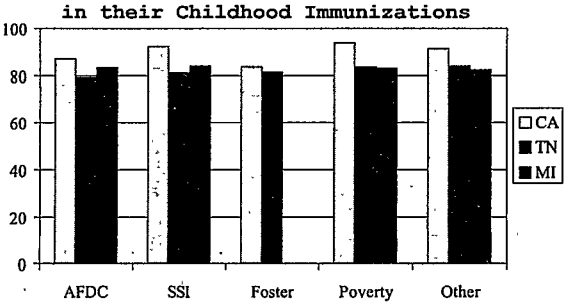


Figure 4: Percentage of Children with EPSDT Visits Who Were Up-to-Date in their Childhood Immunizations



IMPROVING PREVENTIVE SERVICES DELIVERY IN A RURAL HEALTH CARE CLINIC

Charles H. Darby, Mayo Clinic, Mayo Foundation
James M. Naessens, Susan E. Majerus, Gregory L. Angstman, Mary E Campion

Many methods have been tried to increase the use of preventive health services . Mass media appeals, health fairs, mobile outreach units and other methods have been shown to have low cost-effectiveness in predominantly rural areas. This paper will discuss a simple technique used at Mayo Kasson Family Practice Clinic in Kasson Minnesota, and the initial research results on improving the delivery of preventive services there.

Kasson Minnesota has approximately 3,500 residents, the surrounding county about double that number. Kasson is located 15 miles west of Rochester, Minnesota which is home to the Mayo Clinic and a large IBM manufacturing facility. Both communities are approximately 70 miles south of the Minneapolis-St. Paul metroplex.

Kasson is a predominantly an agricultural community. Some light industry and other regional employers complete the economic base for the area.

The Kasson Family Practice Clinic (KMFPC) includes ten staff family practitioners, an appropriate complement of registered and licensed professional nurses, lab personnel, as well as reception, records, and secretarial employees. In addition to these permanent members of the staff, KMFPC hosts 25 residents in family practice from the Mayo Health System. These residents rotate through the facility annually, usually arriving in late summer.

The specific preventive services we studied included: 1)smoking cessation assistance; 2) adult immunizations: pneumococcal pneumonia, influenza, and tetanus-diphtheria; 3) hypertension screening; 4) cholesterol screening; 5) pap smear screenings for cervical cancer; 6) self-administered and clinical breast examinations; and 7) mammography screening. This paper will describe our methods, descriptive findings, prevalence findings and conclusions.

Methods:

All patients 18 and older who received medical care at the Kasson Clinic in 1993 (N=20,371) and in the last three months of 1994 (N=4,171) were identified from Mayo's electronic billing data. A random sample of patients was selected for each period identified. The medical records of these patients were abstracted by registered nurses to determine the level of documentation of each preventive service and the prevalence of each disease precursor identified above.

Upon completion of our abstracting of the 1993 baseline sample (n=249), a Medical Record Form (MRF) of preventive health care questions was introduced at the Clinic. The form is illustrated here as Figure 1. The MRF's questions were addressed by the rooming nurse to each arriving patient. The primary care physician who examined the patient used the MRF as a status summary of the preventive services needed by and provided for the patient.

We extracted a subsequent simple random sample (n=140) from the fourth quarter 1994 encounters at the same facility. This sampling allowed us to study the effects of the MRF during the first three months of its use in the clinic. Both samples were subjected to the same analyses. Table 1 presents a comparison of the two samples pre- and post-MRF.

Comparisons were made on the percent of patients with documented services between the two periods using chi-square analyses to assess the effectiveness of the MRF. A multivariate analysis adjusting for age and sex based on logistic regression was also performed. Additional analysis was conducted to assess whether patients of a particular age group (18-39, 40-64, 65+) were more likely to have a screened disease (e.g. hypertension, excessive cholesterol) or more likely to receive selected services. Trends in the adult immunization rates shown in Figure 4 were based on the total number of each immunization provided at the Kasson Clinic for 1988 through 1994.

Basic Improvement Results

Introduction of the new MRF for preventive services demonstrated success. Documentation improved for adult immunization rates and cholesterol counseling by medical staff. There was improved diagnosis of hypertension in the presence of elevated blood pressures. In fact, documentation rates improved for ten of the eleven items studied. The rates of improvement which were noted between the baseline and subsequent samplings are shown in Figure 2.

Improvements were not limited to documentation. The delivery of preventive services also increased.

Adult immunization rates increased dramatically (Figure 3). Diagnosis of hypertension was improved by 5.3 percent (89.6% to 94.9%). Counseling for cholesterol increased by 14.8 percent (29.3% to 44.1%). The rate of women having a clinical breast examination increased by 3.2 percent across the two samples.

Diphtheria-tetanus immunizations increased from 35 per month in 1992 to over 70 per month in 1994. Influenza vaccinations increased from 235 per year in 1988 to 1,262 per year in 1993 and 1,161 in 1994. Medical record review in 1993 showed that 93 percent of elderly patients at the clinic during that year received the influenza vaccine. The number of pneumococcal vaccines increased

from 33 per year in 1988 to 310 in 1994. Over 60 percent of the elderly clinic patients received pneumococcal vaccinations. It is noteworthy that two of three immunization counts demonstrated their largest single year increase in the year the new preventive services Medical Record Form was introduced. See Figure 4 for the trend in these vaccinations.

Prevalence Findings

Combining the two samples we examined the prevalence of medical conditions and services provided patients in both time periods. Three such findings found to be statistically significant are highlighted.

First, women 65 and older were three times less likely to have had a pap smear in the most recent three years than women in the 40 to 64 age group (p-value =0.007).

Second, older adults (ages 65 and over) were more likely to describe themselves as lifetime non-smokers than were adults in the 18-39 or 40-64 age group (p-value =0.012).

Lastly, senior men and women (in the 65+ age group) were more likely to have abnormally elevated total cholesterol readings than either other age class (p-value<0.001)

Conclusions

We have confirmed three principles by beginning this review process. First, it is apparent that simple medical record tools can assist physicians and nurses in addressing the preventive care needs of their patients. By periodically reviewing and analyzing such data, we will increase our understanding of rural practice and hence provide a better focus for our improvement efforts.

Secondly, documentation of preventive services consideration and delivery can be accomplished in a time-efficient manner by using such a Medical Record Form. The preprinted questions insure uniformity of application.

Lastly, reducing variation in preventive service screening will promote the best use of our vital and limited rural health resources. We will continue to serve a growing rural community by improving our care delivery processes.

As a result of this successful implementation, additional primary care sites in the Mayo Health System have implemented this MRF. Eventually, it is expected that the MRF will become available to all MHS practitioners via the Mayo Electronic Medical

Figure 1: Implemented Medical Record Form (MRF)

Name:_____
Clinic#:____-____ ____ ____-____
D.O.B._____

PREVENTION
1994 1995 1996

	1994		1995		1996	
	Yes	No	Yes	No	Yes	No
Blood Pressure						
Have you had your blood pressure checked in the last year?						
Cholesterol						
Have you had your cholesterol checked in the last 5 years? If yes, which year?						
Were previous levels acceptable?						
Smoking						
Do you smoke?						
Do you wish to quit smoking?						
Immunizations						
Have you had a tetanus immunization in the last 10 years? If yes which year?						
Children						
Immunization status reviewed						
Up-to-date for current year? Check yes when complete for year.						
Persons 65 and older						
Have you had a pneumococcal (pneumonia) vaccination in your lifetime?						
Do you need an influenza vaccination this year?						
WOMEN ONLY						
Do you know how to perform a Breast Self Exam?						
Do you perform monthly Breast Self Exams?						
Have you had a Breast Exam in the last year?						
Have you had a cervical pap smear in the last 3 years?						
WOMEN AGE 40 - 50 ONLY						
Have you had a mammogram in the last 2 years?						
WOMEN AGE 50 AND OVER						
Have you had a mammogram in the last year?						

Record (EMR). Phased introduction of the EMR is scheduled to begin late in 1995.

Identifying and understanding barriers to providing preventive services in a primary care setting will help us to further improve the care we provide our patients, and ultimately potentially decrease the incidence and severity of disease in the regional population. Payors and patients alike expect continuous improvement in the quality of care we deliver in rural settings. Consistently measuring our efforts will reaffirm our commitment to their expectations.

Table 1: Comparison of Disease Prevention/Detection/Management Results Baseline and Post MRF Analyses

	Baseline n(%)	Subsequent n(%)
Smoking Status		
Not documented	13 (5.2)	3 (3.1)
Non-smoker	135 (54.2)	78 (79.6)
Past smoker	49 (19.7)	5 (5.1)
Current smoker	52 (20.9)	12 (12.2)
Smoking Advice		
Not documented	22 (42.3)	1 (8.3)
Patient refused	1 (1.9)	6 (50.0)
MD/RN documented quitting advice	29 (55.8)	5 (41.7)
Smoking Management		
Not documented	31 (59.6)	2 (16.7)
Nonspecific documentation	1 (1.9)	0 (0.0)
Patient self management	6 (11.5)	10 (83.3)
Written materials provided to patient	2 (3.9)	0 (0.0)
Nicotine gum ordered	2 (3.9)	0 (0.0)
Nicotine patch ordered	1 (1.9)	0 (0.0)
Smoking cessation program referral	5 (9.6)	0 (0.0)
Any 2 or more of prior 4 choices		
Other management effort	4 (7.7)	0 (0.0)
Smoking Results		
No documentation	24 (46.2)	6 (50.0)
Smoking stopped	3 (5.8)	0 (0.0)
Smoking reduced	4 (7.7)	0 (0.0)
Smoking unchanged	21 (40.4)	6 (50.0)
Cholesterol		
Documentation of screening in most recent 5 years	143 (57.4)	83 (84.7)
Screening result was normal	90 (36.1)	49 (50.0)
Screening result was abnormal (total cholesterol ≥ 242)	50 (20.1)	19 (19.4)
Patient declined or done more than 5 years ago	3 (1.2)	15 (15.3)
Cholesterol Test Result Follow-up		
No documentation or no follow-up	75 (54.6)	52 (41.0)
Patient counseled by MD/RN	41 (29.7)	30 (30.6)
Patient referral to dietitian	2 (1.4)	0 (0.0)
Patient given written material	2 (1.4)	5 (5.1)
Any of prior 3 choices	18 (13.0)	11 (11.2)
BP Screening		
Not documented	21 (8.4)	1 (1.0)
Not hypertensive (BP ≤ 139/89)	134 (53.8)	68 (69.4)
Patient diagnosed hypertensive	68 (27.3)	24 (24.5)
BP ≥ 140/90 but not documented hypertensive	26 (10.4)	5 (5.1)
Hypertensive Management		
No documentation	21 (22.3)	0 (0.0)
Counseling only	12 (12.8)	5 (17.2)
Counseling and medications		
Patient declined treatment	61 (64.9)	24 (82.8)
Immunizations:		
Pneumococcal		
Not documented	37 (14.9)	30 (30.6)
Not applicable	173 (69.5)	28 (28.6)
Given	37 (14.9)	33 (33.7)
Patient declined	2 (0.80)	7 (7.1)
Influenza		
Not documented	184 (73.9)	21 (21.4)
Not applicable	0 (0.0)	35 (35.7)
Given	58 (23.3)	32 (32.7)
Patient declined	7 (2.8)	10 (10.2)
DT		
Not documented	127 (51.0)	20 (20.4)
Not applicable	0 (0.0)	2 (2.0)
Given	100 (40.2)	67 (68.4)
Patient declined	21 (8.4)	6 (6.1)
Immunization Education		
Not documented	235 (94.4)	52 (53.1)
Not applicable	12 (4.8)	2 (2.0)
Given	2 (0.80)	20 (20.4)
Patient declined	0 (0.0)	24 (24.5)
Pap Smear Screening		
No documentation	32 (23.0)	8 (11.8)
Done ≤ 3 years ago at Mayo	93 (67.0)	51 (75.0)
Done > 3 years ago at Mayo	11 (7.9)	8 (11.8)
Patient report done ≤ 3 years ago elsewhere	1 (0.7)	1 (1.5)
Patient report done > 3 years ago elsewhere	2 (1.4)	0 (0.0)
Pap Smear Results		
No documentation	39 (28.1)	10 (14.7)
Mayo normal	96 (69.1)	55 (80.9)
Mayo abnormal with follow-up	3 (2.2)	0 (0.0)
Mayo abnormal without follow-up		
Patient report normal elsewhere	0 (0.0)	3 (4.4)
Patient report abnormal elsewhere		
Other	1 (0.7)	0 (0.0)
Clinical Breast Exam		
No documentation	44 (31.7)	7 (10.3)
Patient declined	3 (2.2)	12 (17.7)
Done in most recent 12 months	63 (45.3)	33 (48.5)
Done between 13 and 36 months prior to visit	21 (15.1)	10 (14.7)
Done more than 36 months prior to visit	7 (5.0)	5 (7.4)
Not applicable	1 (0.7)	1 (1.5)
Breast Self Exams		
No documentation	121 (87.1)	10 (14.7)
Patient instructed in office visit by MD/RN	14 (10.1)	51 (75.0)
Patient instructed in BSE class/program	3 (2.2)	0 (0.0)
Patient declined or did not attend class	1 (0.7)	7 (10.3)
Abnormal Mammography Findings		
No documentation	71 (51.1)	22 (32.4)
Normal - follow-up documented	4 (2.9)	6 (8.8)
Abnormal - follow-up documented	45 (32.4)	28 (41.2)
Normal - no follow-up	17 (12.2)	12 (17.7)
Abnormal - no follow-up	2 (1.4)	0 (0.0)
Breast Self Exam		
No documentation	121 (87.1)	10 (14.7)
MD/RN instructed patient	14 (10.1)	51 (75.0)
Patient attended class for instruction	3 (2.2)	0 (0.0)
Patient declined / patient did not attend class	1 (0.7)	7 (10.3)

Figure 2: Documentation Improvement in the Patient Medical Record from Baseline to Post MRF Implementation.

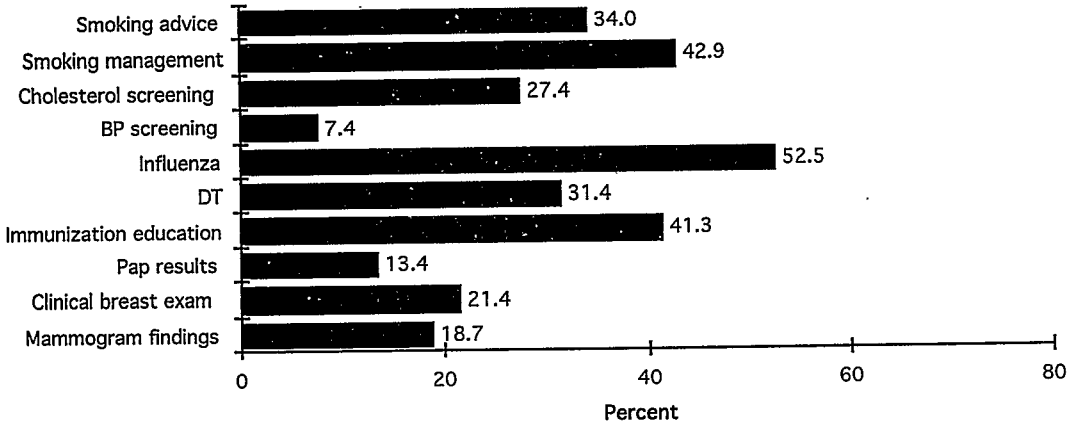


Figure 3: Adult (Age 18 and Over) Immunization Rate Improvement from Baseline to Post MRF Implementation.

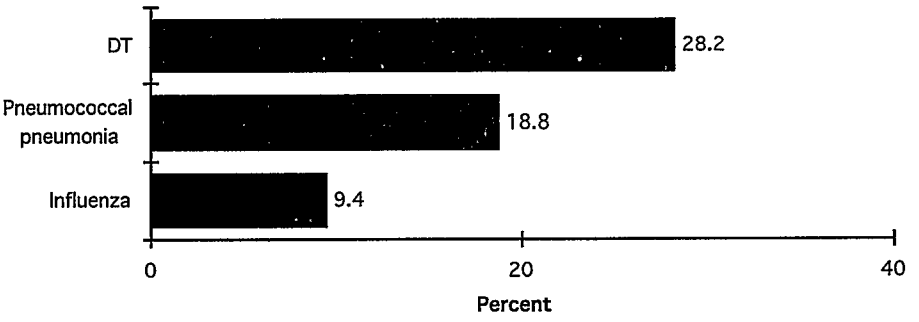
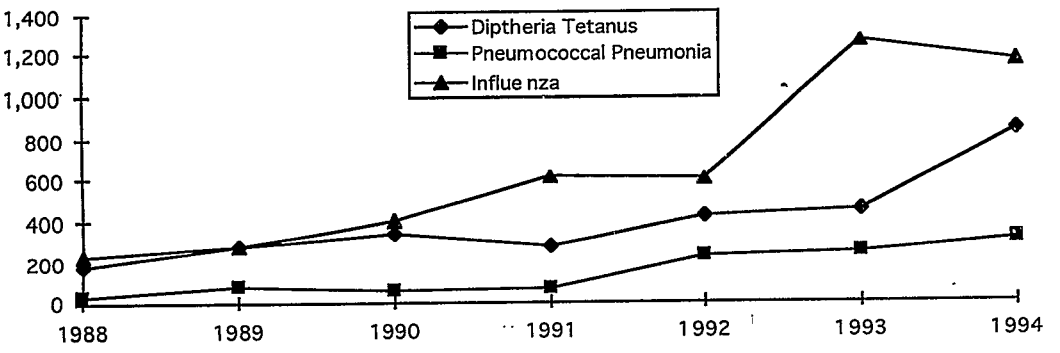
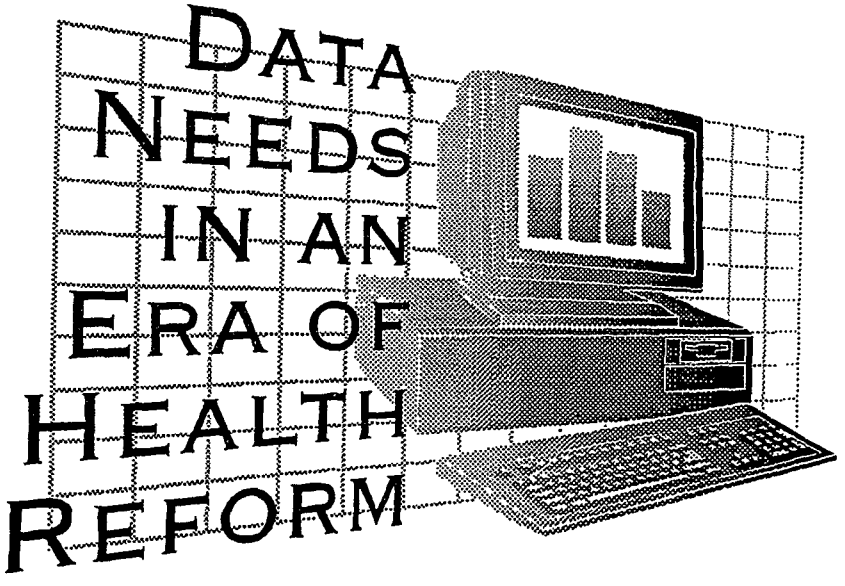


Figure 4: Trends in Vaccinations Administered Mayo-Kasson Family Practice Clinic, 1988-1994



Session R

Persons with AIDS



THE NATIONAL DATABASE FOR HIV-INFECTED AMERICAN INDIANS, ALASKA NATIVES, AND NATIVE HAWAIIANS

David D. Barney, National Native American AIDS Prevention Center

In September 1994, the National Native American AIDS Prevention Center (NNAAPC) developed a national database composed of information about American Indians, Alaska Natives, and Native Hawaiians who are infected with HIV. At NNAAPC, the database is referred to as the "national database" since data are gathered about individuals from many diverse geographic regions and tribal communities throughout the United States.

History of NNAAPC

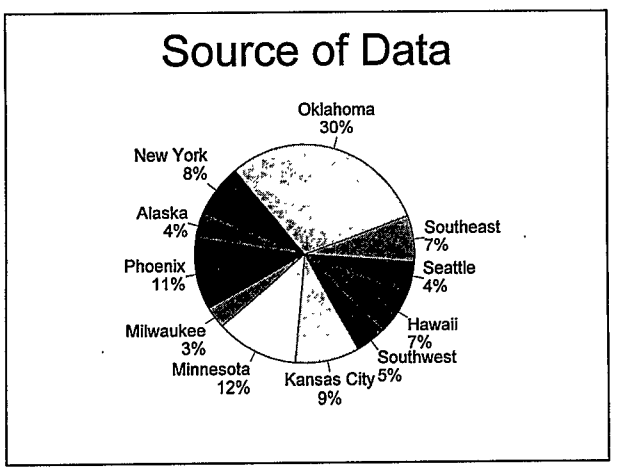
NNAAPC was founded in 1988 by a grant from the Centers for Disease Control and Prevention (CDC). The mission of the agency has been to stop the spread of HIV and related diseases, including sexually transmitted diseases and tuberculosis, among American Indians, Alaska Natives, and Native Hawaiians by improving their health status through empowerment and self-determination. Programming efforts at that time were exclusively prevention oriented. However, in 1991, NNAAPC was awarded a grant from the Health Resources and Services Administration (HRSA) to operate a case management demonstration project for HIV-infected American Indian people in the state of Oklahoma. Subsequently, HRSA has expanded the capability of NNAAPC to serve tribal communities by facilitating the development of twelve local community-based programs nationwide. These programs serve as data collection sites for NNAAPC research and model development activities.

Composition of the Database

Prior to the development of this database, there was no data systematically collected exclusively for the purpose of describing or monitoring of health of HIV-infected American Indian, Alaska Native, or Native Hawaiian individuals. Thus, the national database is the first effort to identify the health characteristics and service needs specifically for these populations. Until this database was created, there was no consolidated source of information to describe the demographic characteristics of those American Indians, Alaska Natives, or Native Hawaiians infected with HIV. At present, the national database serves as a valuable research tool to address basic HIV-care related questions about these populations. The database will also be essential for future inquiry into more complex research questions. However, the main purpose of the database has been to develop the baseline information that is essential for health planners and policy makers to address the health and medical needs of these at-risk populations.

The database is comprised of two types of variables. First, there are 35 variables that describe the demographics of those individuals in the database. Some of these demographic variables also serve as baseline data for longitudinal analyses. Second, there are 319 variables that monitor an individuals' health status over a two year period. These variables are collected on a bi-monthly basis.

As of July 1995, the national database has a total of 238 cases. These cases increase monthly as new cases are continuously added to the database. The sample itself is a non-representative convenience sample composed of clients from eleven NNAAPC-sponsored HIV-care case management programs. All of these programs are funded by NNAAPC. The largest program, the Ahalaya Project, is located in the state of Oklahoma with offices in Tulsa and Oklahoma City. The other sites include programs in the states of Alaska, Hawai'i, North Carolina, New York, Wisconsin, Washington, Arizona, Kansas, and Minnesota.

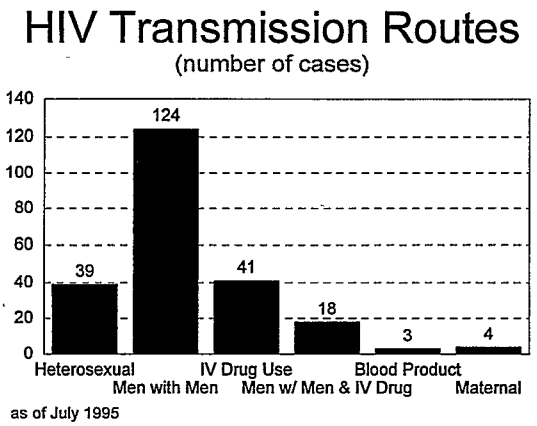


Demographic Characteristics of Clients

The sample in the database is composed of clients of HIV-case management programs. The demographic profile of these individuals is predominately male (82%). There are four pediatric HIV/AIDS cases ranging from infant to four years of age. In the adolescent/adult category, ages range from 16 to 59 years. The adolescent/adult mean and median age are approximately the same at 34 years.

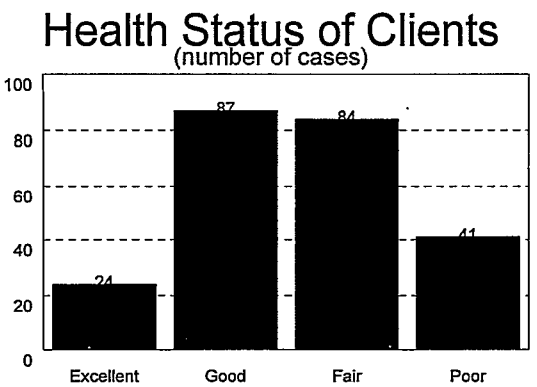
HIV transmission routes are recorded in the database using categories consistent with CDC surveillance reporting. The pattern of HIV infection routes appears to be similar to many other

population groups. The largest transmission route was men having sex with men comprising 54% of the sample. An additional 8% contracted HIV through men having sex with men and IV drug use. The sample has 18% acquired HIV from IV drug use alone. Seventeen percent acquired HIV through heterosexual contact. Finally, 1% contracted HIV from blood products and 2% contracted HIV through maternal transmission.



The health status of clients as they enter into case management services (and the database) is an important baseline measurement to determine service effectiveness or HIV pathogenesis. Upon entry into the data base, adolescent/adult clients have a mean CD4 count of 341 with a range from 0 to 1,100. At the most current measurement of CD4 counts, the mean decreases to 297 with a range from 0 to 1,003.

Case workers report that 47% of clients have either good or excellent health. Another 35% have fair health, while the 18% remaining have poor health.



Another measure of health status has been developed by the CDC and is included as a variable in the database. Specifically, the 1993 revised classification system for HIV infection has been used for comparability with other health databases. This variable identifying the HIV/AIDS case definition is illustrated in Table 1.

TABLE 1. HIV/AIDS STATUS

	Count	%
Asymptomatic HIV	84	35.9%
Symptomatic HIV	68	29.1%
AIDS Status	82	35.0%
Total	234	100.0%

The database also contains variables that identify the health and social service programming needs of individuals. These variables identify social indicators and suggest treatment needs. Twenty-two percent of clients in the database have a history of mental illness. Sixty-two percent have a history of alcohol abuse while 51% have a history of drug abuse. Twenty-six percent of clients have a history of being homeless.

Important Preliminary Findings

Two issues are particularly noteworthy in this data set. First, the presence of American Indian, Alaska Native, and Native Hawaiian women in the database are over-represented when compared with the infection rates of women in non-minority populations. However, the 18% of females in the database is approximately consistent with many other minority populations. Second, there is a low usage (48%) of the US Public Health Service, Indian Health Service (IHS) among the HIV-infected sample in this database. This suggests that despite important needs for medical care, American Indians, Alaska Natives, and Native Hawaiians may be reluctant or unable to access IHS services. This finding is in contrast to a popularly held belief that "American Indians have their health care needs met by the IHS." This database reveals that slightly more than one-half of those needing HIV care were unwilling or unable to access IHS services supporting the concept that the IHS functions as the medical-care provider of "last resort."

The first developmental phase of the national database is now complete and still continuing to progress with the ongoing collection of basic demographic data as previously described. Over the next two years, analysis will be conducted of other variables that measure the longitudinal aspects of client status in a case management program designed for American Indian, Alaska Native, and Native Hawaiian clients.

THE ONTARIO HIV OBSERVATIONAL DATABASE: INFORMATION FOR RESEARCH AND PLANNING FOR PERSONS LIVING WITH HIV IN ONTARIO

Robert Throop, Sunnybrook Health Science Center

Paper not available for publication.

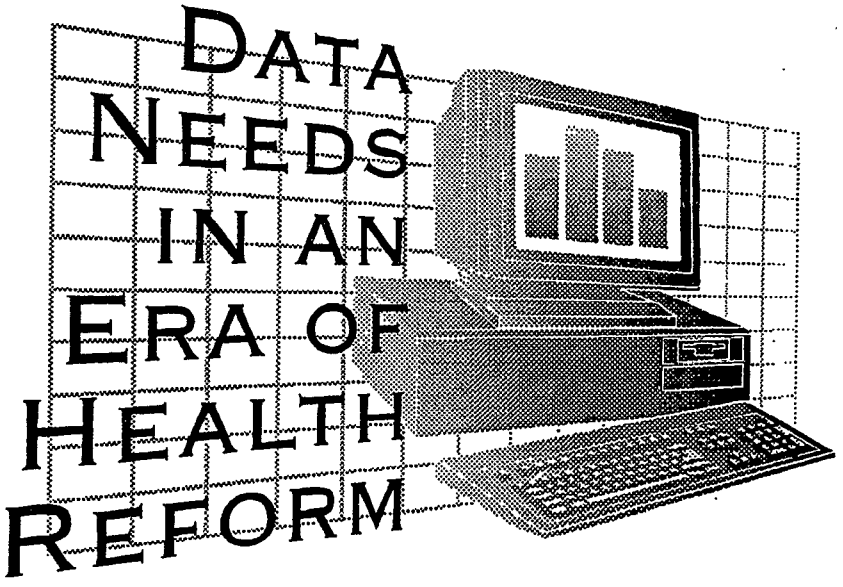
USING SURVEILLANCE DATA IN COMMUNITY PLANNING FOR HIV PREVENTION

Cibele Barbosa
Centers for Disease Control and Prevention

Paper not available for publication.

Session S

Measuring the Effects of Race and Class



EVALUATION OF MALE EXCESS AMONG PRETERM BIRTHS: A POSSIBLE ETIOLOGIC MARKER

Michael Cooperstock, University of Missouri School of Medicine

Paper not available for publication.

RACE, CLASS, GENDER AND CANCER

Nancy Breen, National Cancer Institute
Alex Ching

The primary measures for assessing the impact of cancer in the general population are the age-adjusted rates of incidence (number of new cases per year per 100,000 persons) and mortality (number of deaths per 100,000 persons). Mortality from cancer is higher for black than white Americans. The cancer mortality rate for white men between 1986-90 was 213.2, and for black men it was 315. For white and black women it was 139.2 and 165.7 respectively. Incidence rates for the same period were 450.4 and 540 for white and black men and 345.8 and 328.8 for white and black women.(1) Higher mortality for black women is especially troubling because incidence is lower for black than white women.

Why is mortality from cancer higher for black than white Americans? The literature has suggested a number of reasons:

- —socioeconomic status
- —late stage of disease at diagnosis
- —diagnostic and treatment delays
- —treatment differences
- —biological and constitutional factors
- —environmental factors.

This research addresses the question to what extent are race differences in cancer mortality attributable to SES differences? One study found race differences in mortality for all cancer sites aggregated are entirely explained by age, sex, marital status, family size and income.(2) Because cancer is a family of related diseases, rather than a single disease, cancer is usually analyzed by particular site.

This paper examines the health care delivery system and tests a two-part socioeconomic hypothesis. First, mechanisms related to economic inequality perpetuate pre-existing racism in the health care delivery process. Second, this process is cumulative.

Our research plan is to examine two case studies, breast and cervical cancer, for which screening has a proven mortality benefit. Breast cancer was the most common cancer among women in 1990.(3) We will examine the extent to which the literature has analyzed race and SES factors in the context of health care delivery for cancer. We will then evaluate literature and suggest refinements to data collection or analytical methods.

For breast and cervical cancer, a person diagnosed with cancer is more likely to survive if the cancer is detected early and treated promptly. However, white women diagnosed with breast or cervical cancer tend to survive longer than black women. A key indicator of cancer prognosis is stage at the time of diagnosis.

There are four stages at which cancer may be diagnosed. These include 1) in situ: a neoplasm with all characteristics of malignancy except invasion (data not published by NCI), 2) localized: an invasive malignant neoplasm confined entirely to the organ of origin, 3) Regional: an invasive neoplasm which a) extends beyond the organ of origin directly into surrounding tissue or b) involves regional lymph nodes or c) both, 4) Distant: an invasive neoplasm which has spread to part of the body remote from the primary tumor site.

Table 1 shows 5-yr survival by stage for breast and cervical cancer diagnosed between 1983-87 and the percent of black and white women diagnosed at each stage.(1)

Table 1

	White Women		Black Women	
	Percent surviving	Percent diagnosed	Percent surviving	Percent diagnosed
		BREAST CANCER		
Local	94	53	84	42
Regional	73	36	57	42
Distant	19	7	10	10
		CERVICAL CANCER		
Local	90	51	86	36
Regional	53	32	45	41
Distant	13	10	14	14

The combination of the result of differentials in survival and the percent black and white women diagnosed at each stage of cancer results in mortality rates of 22.4 and 26.1 for breast cancer and 2.3 and 6 for cervical cancer for white and black women respectively. Later stage breast and cervical cancer diagnosis ap-

pears to be part of the explanation for higher mortality from breast cancer for black than white women and SES is associated with stage of diagnosis.

Studies have shown that SES explains some or all of race differences in breast or cervical cancer survival. For example, a recent study by Eley using data from the SEER special black/white study found the mortality risk of breast cancer was 2.1 times greater for black than white women. Forty percent of this difference was due to later stage at diagnosis for black women. The authors concluded that sociodemographic variables appear to act largely through racial differences in stage at diagnosis.(4) Other studies found that while race was a significant predictor of cancer survival, when an indicator of SES was included in the model, race ceased to be significant or was attenuated.(5-12)

Standard medical care for breast or cervical cancer includes screening (for the entire population), diagnosis that includes staging, treatment, and post-treatment care and monitoring. Literature on access to care at each point during course of standard treatment for race and SES differences will be examined.

ACCESS TO STANDARD CARE

Screening

Screening modalities for breast cancer include mammography, breast physical examination (performed by a health care provider) and breast self-examination. Mammography has been shown to reduce breast cancer mortality by approximately thirty percent in clinical trials(13) and is therefore generally considered the most reliable breast cancer screening modality. Population studies have shown the Pap smear to be effective for cervical cancer; if women were regularly screened, it could lead to a near eradication of cervical cancer.

Rates of utilization of screening are monitored in the National Health Interview Survey. Recent studies show that SES accounted for differences by race in mammography use.(14,15) However, it did not account for differences in use of Pap smears by race or Hispanic ethnicity.(16)

Diagnosis

Racial differences in breast cancer stage at diagnosis were explained by Census-tract level SES(17) or private health insurance status.(18) Cervical cancer stage differences are associated with both race and SES(19,20)

Treatment

For breast cancer, Bain(21) found no racial difference in the percent of women with local or regional disease who received surgery; for women with distant disease, there was a racial difference. Black women with advanced disease were less likely than white women to receive surgery and their mortality was higher than white women with advanced disease.

SUMMARY

SES appears to underlie racial differences at each stage of cancer care. However, it is difficult to draw firm conclusions from the literature because many studies examine only race or only SES (or neither). To draw firm conclusions, additional studies that examine race and SES simultaneously are needed.

Consequently, we cannot systematically evaluate our hypothesis. Though more than sixty articles were reviewed, and the articles cited suggest the importance of social class in obtaining prompt access to standard care for breast and cervical cancer, the literature does not routinely examine race and social class for both cancers at each point in the process of cancer care so the hypothesis can not be evaluated. We found no studies on treatment for cervical cancer or post-treatment care and follow up for either cancer that analyzed race and SES.

Except for NHIS data on screening, few cancer sources collect family size, income, education, health insurance status or other variables related to SES or social class.

RECOMMENDATIONS

SES variables need to be routinely collected on health surveys. This data can be collected from respondents. Where medical abstracts are the source of information, detailed insurance information can be collected as a rough proxy for SES. Geocoding at the Census tract level also provides a useful proxy for SES data when individual data are not available.

SES needs to be explicitly compared with race. Public health studies often use race as a proxy for social class. While a

far greater proportion of blacks and Hispanics than whites are poor, there are social class differences by race and ethnicity. These two variables need to be routinely analyzed separately and explicitly in order to sort out the effects of race and the effects of social class.

SES needs to be tested as an explanatory variable because it is subject to policy intervention. Epidemiological studies often use SES as a control variable. Social class (and income distribution) are social phenomena that can be altered by public policy interventions. Public policy is more likely to succeed if it is based on scientific evidence, however, and currently we do not have the evidence we need to design sound public policy.

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USE OF DEATH CERTIFICATE OCCUPATION DATA FOR ANALYSES OF SOCIAL CLASS AND MORTALITY: STRENGTHS AND LIMITATIONS

Elizabeth Barnett
North Carolina State Center for Health and Environmental Statistics

Paper not available for publication

EXAMINING THE BLACK-WHITE ADULT MORTALITY DISPARITY: THE ROLE OF RESIDENTIAL SEGREGATION

Chiquita Collins and David R. Williams, University of Michigan

During the past several decades the United States has experienced substantial improvements in the health of all of its citizens but African Americans[1] continue to experience higher rates of mortality than whites. Table 1 indicates how pervasive racial disparities in mortality are. It presents the overall death rates for blacks and whites, and the black-white ratios for the 15 leading causes of death in the United States in 1990. A ratio greater than 1 indicates that the death rate for blacks is higher than for whites. With the exception of suicides and chronic obstructive pulmonary diseases, mortality rates from all causes of death were higher for blacks than for whites. The differences are small for some conditions such as atherosclerosis and accidents, but substantial for others, such as kidney disease, perinatal conditions, AIDS and homicide.

Table 1. Age-Adjusted Death Rates for the 15 Leading Causes of Death By Race in the United States, 1990 (per 100,000 Population)

Cause of Death	Blacks	Whites	B-W Ratio
1. Heart Disease	213.5	146.9	1.45
2. Cancer	182.0	131.5	1.38
3. Stroke	48.4	25.5	1.90
4. Accidents	39.7	31.8	1.25
5. Pulmonary	16.9	20.1	0.84
6. Pneumonia and	19.8	13.4	1.48
7. Diabetes	24.8	10.4	2.38
8. Suicide	7.0	12.2	0.57
9. Liver Disease	13.7	8.0	1.71
10. HIV-AIDS	30.6	9.8	3.12
11. Homicide	39.5	5.9	6.69
12. Kidney Disease	10.8	3.6	3.00
13. Septicemia	9.5	3.5	2.71
14. Atherosclerosis	3.1	2.7	1.15
15. Perinatal	16.2	5.2	3.12

Prior research has provided important evidence about the existence and magnitude of the black-white mortality gap, but how and why this disparity persists is not well understood. Differences in social and economic status (Adler, et al. 1993; Pappas et al. 1993), accessibility and quality of medical care (Blendon, et al. 1989), working conditions, environmental factors, as well as genetic and life style factors (Otten, et al. 1990) have been proposed as explanations of the mortality gap between blacks and whites (Williams and Collins, 1995). The empirical evidence to date suggests that these factors have important but limited explanatory value in accounting for racial differentials in mortality. There is growing interest in identifying the ways in which racism is causally prior to these traditional factors and operates additively and interactively with them to influence the observed rates of disease (Krieger et al. 1993; Cooper 1993; Williams et al. 1994). A central aspect of racism is residential segregation, the extent to which blacks live separately from whites (Massey and Denton, 1993).

The literature proposes two major mechanisms by which racial residential segregation may affect the lives of African Americans (Massey and Denton, 1993, Wilson 1987). First, it creates and perpetuates spatially concentrated poverty (Massey and Denton, 1993). Second, it socially isolates African Americans from white society (Wilson, 1987). Both mechanisms can adversely affect health.

Because of the concentration of poverty, poor African Americans may be different to the poor of other groups. In many urban areas there is a high degree of segregation combined with a high rate of poverty, and low levels of education and job skills (Massey et al. 1991). Living in poor segregated neighborhoods can include dilapidated housing, poor nutrition, unemployment and underemployment, low-wage jobs, poor education, poor police protection, crime, high cost of living, fatal injuries, and a lack of health insurance and access to basic health services. African Americans living in segregated neighborhoods are exposed to these conditions more frequently than their white counterparts. On average, poor African Americans are increasingly concentrated in neighborhoods with bad living conditions, while poor whites are more evenly dispersed throughout the city, with many residing in relatively safe and comfortable neighborhoods (Wilson 1987). The risk of teenage pregnancy and early sexual intercourse is high in poor neighborhoods (Hogan and Kitagawa 1985). Crane (1991) found that as the percentage of low-SES workers in a poor black neighborhood rose there was an increasing likelihood of dropping out of high school and having a teen birth. Similarly, Massey et al. (1991) report that increases in neighborhood poverty rates are associated with increases in male joblessness and the percentage of female-headed households.

Residential segregation has an important role in perpetuating social problems in predominantly black neighborhoods because the degree of isolation from mainstream society creates a neighborhood environment among African Americans that is substandard in quality when compared to whites. African Americans living in highly segregated areas are unlikely to have a protective barrier to buffer them from exposure to adverse living conditions such as drug trafficking and illicit drug abuse, high rates of crime, poor quality schools, alcoholism, disproportionate number of liquor stores, dilapidated housing, and vacant lots used as garbage dumps. Table 2 shows characteristics that are commonly found in predominantly poor, black neighborhoods and potential health risk factors as a result of racial residential segregation.

On average there are vast disparities between blacks and whites in the social and economic composition of their neighborhoods. Compared to white neighborhoods, African American neighborhoods are more likely to have numerous fast food restaurants, auto mechanic shops, liquor stores, beauty shops and check cashing centers. Goods and services provided in black neighborhoods are on average worse in quality than those in white neighborhoods. For example, since supermarkets are located outside most black neighborhoods, many blacks are limited to shopping for food at local groceries and corner stores where food is more expensive but lower in quality than in suburban supermarkets. Blacks often pay 15% more for food and 22% more for vegetables in black neighborhoods (Troutt 1993). Wilson (1987)

Table 2. Neighborhood characteristics that are common in predominantly poor, black neighborhoods and potential risk factors/health outcomes that are affected by such neighborhoods as a result of residential segregation.

Neighborhood Characteristics	Health Outcomes
Housing Dilapidated housing, public housing Boarded-up housing, poor plumbing, poor heating, poor ventilation, poor maintenance	Tuberculosis, Asthma, Chronic Bronchitis, Accidents
Employment low skill/training, low education attainment, access to jobs (suburbanization of low skill high wage jobs)	Cirrhosis of the liver and chronic liver disease (alcoholism), Occupational Accidents, Exposure to Toxins
Education ratio of students to teacher, overcrowded classes, poor student performance, high drop-out rates, "tracking"	Cirrhosis of the liver and chronic liver disease (alcoholism), illicit drug use, cigarette smoking
Disproportionate # of liquor stores marketing and selling strategies to sell hard-liquors and malt liquors, (beer with high alcohol content)	Cirrhosis of the liver and chronic liver disease
Police Protection/Safety high rates of victimization of violent crimes (e.g. assault w/weapon, homicide, robbery)	Homicide, accidents
Informal support mechanisms ≤ 2 friends high levels of social isolation high rates of single-female headed households	Suicide, Cirrhosis of the liver and chronic liver disease (alcoholism), illicit drug use
Quality of food higher cost, poorer quality (e.g. spoiled meat, welted vegetables)	Hypertensive disease, Diabetes, Cancer, Obesity
Cost of living high cost for rent, high taxes, fixed incomes	Lack of resources for adequate goods and services

contends that social isolation produced by the absence of social interaction between African Americans and white Americans adversely impacts the living conditions in highly concentrated poor black neighborhoods.

According to this view limited exposure to white society (a result of residential segregation) ensures that poor African Americans lack direct linkages to quality services from societal institutions. For example, because residence is associated with educational opportunities, racial residential segregation perpetuates an educational disadvantage for poor blacks by exposing them to inferior schools (Coleman, Kelley & Moore 1975, Farley 1978, Farley & Taueber 1975). In urban schools, African American students are more likely to be placed (or "tracked") in low-ability and non-college preparatory programs. Black students that are tracked are placed in classrooms where the teachers' low expectations contribute to lower levels of school performance and attainment (Jaynes & Williams 1989). In addition to tracking, blacks are twice as likely as whites not to graduate from high school (Jaynes & Williams 1989). Inferior schools in combination with low educational aspirations limit African Americans' access to good employment opportunities and other formal networks and institutions thereby creating a disadvantage in competing for employment opportunities with desirable salaries and working conditions. The result is that employed African Americans are disproportionately found in low-skilled and low-paid occupational positions. In short, African American neighborhoods that are socially isolated from mainstream society are disproportionately affected by social and economic problems, that occur less frequently in predominantly white neighborhoods. These include low-achieving schools, joblessness, low rates of marriage, and crime which in turn, have deleterious effects on their quality of life.

Studies that have examined the association between segregation and health have consistently found segregation to be a predictor of variation in mortality. Yakauer (1950) reported that infant mortality rates for blacks and whites were highest in the most segregated areas (all-black areas). More recent studies have found that residential segregation was significantly related to health status for blacks but not for whites for the following death rates: infant mortality (LaVeist 1989; Polednak 1991), all-cause mortality for persons aged 15-24 and 65-74 (Polednak 1993), and homicide (Rosenfield 1986; Potter 1991). LaVeist (1989) found a positive association between residential segregation and black infant mortality, but an inverse association with white infant mortality. In a similar study, Polednak (1991) found that the most important predictor of the black-white difference in infant mortality in 38 standard metropolitan statistical areas (SMSAs) was an index of residential dissimilarity, independent of the difference in median family income and the prevalence of poverty.

Logan and Messner (1987) found a significant relationship between residential segregation and homicide in *suburban* rings of 54 metropolitan areas in 1980 and not in 1970. In contrast, Rosenfield (1986) found that residential segregation had a positive association with homicide in standard metropolitan statistical areas (SMSAs) for 1970. Potter reported that the level of residential isolation had a significant effect on the homicide differential between blacks and whites in 1980 for 27 metropolitan areas. In a recent study, Polednak (1993) examined the association between residential segregation and age-specific all-cause mortality rates and found that the level of residential segregation was a positive predictor of the black-white ratio for persons between the ages of 15 and 44. In a study that only analyzed the effects

of racial residential segregation on *black* homicide, Peterson and Krivo (1993) found that racial residential segregation had a strong significant positive effect on *black* homicide rates for central cities of SMSAs in 1980.

In this paper we examine the extent to which residential segregation can account for the black-white adult mortality disparity. Unlike previous studies of all-cause mortality, we used cities as the unit of analysis instead of standard metropolitan statistical areas (SMSAs) which increased our sample size considerably when compared to previous studies.

Data and Methods

Study Population

This study used data from the Mortality Detail Files, collected by the National Center for Health Statistics (NCHS), and from the 1990 United States Census to analyze the relationship between residential segregation and the black-white mortality gap. Our unit of analysis is U.S. cities with a population of at least 100,000 in 1990 and with an African American population of at least ten percent. These criteria yielded a sample size of 107 cities. Only mortality for blacks and whites who were at least fifteen years of age at time of death were analyzed. Mortality rates were disaggregated into three age groups: 15 to 44 years of age; 45 to 64 years of age; and 65 years and older. These rates were then adjusted for the age distribution of the 1990 U.S. population using "direct" standardization techniques to obtain race- and gender- specific age standardized mortality rates. All race specific information obtained from the Census correspond with the racial categories of the mortality data. Race was defined as either "black" or "white", excluding ethnic distinctions (i.e., non-Hispanic).

Measures

Dependent Variable

The dependent variable is the difference between the city's black and white adult mortality rate per 100,000 population. The black-white mortality disparity will be less than zero if the white mortality rate is greater than the black mortality rate, and greater than zero if the black rate is higher.

Independent Variables

Six independent variables were selected as determinants of the black-white mortality gap: one measure of residential segregation, four measures ofsocioeconomic status, and population size. Table 3 lists the independent variables and describes how they were operationalized.

Racial residential segregation was measured by calculating the index of dissimilarity for each city (Massey & Denton 1987). Theoretically, levels of residential segregation between blacks and whites range from 0 to 100. It takes on the maximum value of 100 in a situation where the racial composition is completely segregated. A value of zero indicates that blacks and whites are randomly distributed across all census blocks in a given city. The measures of socioeconomic status and population size are straightforward. These variables are similar to those used in earlier studies of residential segregation and mortality. Education is measured as the black-white difference in the proportion of persons older than 24 years of age that graduated from high school. Occupational status is measured by obtaining the black-white difference in the proportion of persons older than 15 years of age employed in professional and managerial occupations. Income is measured by obtaining the black-white difference in median family income in 1989 dollars. Because the total black and white population in cities varied considerably in size, in all of our analyses we controlled for population size by using the natural log of the total city population.

Statistical Analysis

This report used ordinary least squares (OLS) analyses to assess the relationship between racial residential segregation and the black-white all-cause mortality gap. All analyses are reported separately for men and women for the three age categories described earlier.

Results

The means, medians, standard deviations, minimum and maximum values for each variable are shown in table 4. The index of dissimilarity in 1990 varied by a factor of almost three, ranging from 31.1 (Aurora, Colorado) to 88.3 (Cleveland, Ohio). On average, the black-white gap in education, income, and occupational status was greater in highly segregated cities than in moderate to low segregated cities.

For both men and women, the black-white mortality gap varied considerably across the 107 U.S. cities. The average age specific mortality rate (per 100,000 population) was approximately twice as great for blacks as for whites between the ages of 15-44 and 45-64; the mortality gap was smaller for individuals aged 65 and over. Durham, North Carolina had the largest black-white mortality gap for women aged 15-44, and a moderately high segregation index (60.0), while the largest mortality gap among men was evident in New Haven, Connecticut with a slightly higher segregation index (62.2). For men and women between the ages of 45-64, the largest black-white mortality gap was present in Berkeley, California and Virginia Beach, Virginia respectively.

Table 3. Independent Variables for the Analysis of the Black-White Racial Gap in Mortality

Variables	Operationalization
Segregation	
Dissimilarity	Index of dissimilarity of black-white residential segregation across census blocks
SES	
B-W income gap	Difference of black-white median family income (in 1989 dollars)
B-W education gap	Difference of black-white population older than 24 with at least a high school education
B-W occupation gap	Difference of black-white employed persons in professional and managerial occupations
Population	Natural log of total black and white population

Table 4. Means, Standard Deviations, and Ranges for Residential Segregation and Socioeconomic Status Indicators by Race: U.S. Cities (100,000 population or more)

	Segregation	Education (%)		Income (1989 dollars)		Occupation (%)		Poverty (%)	
		Black	White	Black	White	Black	White	Black	White
Median	65.9	64.4	79.9	$21,028	$36,691	16.5	30.2	28.1	6.7
Mean	65.4	64.7	77.9	$21,219	$37,837	17.5	31.6	28.3	7.6
Standard Deviation	11.2	6.86	8.99	$4,397	$7,869	3.5	8.3	7.1	3.6
Range:									
Minimum	31.1	39.7	42.5	$13,883	$22,050	11.0	13.2	10.6	1.9
Maximum	88.3	87.3	96.3	$33,410	$76,074	29.5	62.0	43.6	19.6

African Americans living in highly segregated cities, on average, were less likely to graduate from high school, earn high incomes, and hold managerial and professional occupations than blacks living in least segregated cities. The pattern was similar for whites for education, but whites living in least segregated cities had slightly higher levels of income and occupational status than their counterparts in highly segregated cities.

Table 5 presents the relationship between residential segregation and the black-white mortality gap for women. Residential segregation has a marginally significant positive association with the black-white mortality gap for women aged 15-44. However, this relationship was non-significant for women between the ages of 45-64 and 65 and older. The pattern for men under the age of 65 was similar to that of women (Table 6). The residential segregation index was positively related to the black-white mortality gap for men aged 15-44 ($p<.01$) but unrelated for those in the 45-64 age category. Thus, for both males and females in young adulthood and early middle age, the black-white gap in mortality tends to be greater in cities that have high levels of residential segregation. In contrast, it is striking that although the association between segregation and the black-white mortality gap is significant for men aged 65-85+, the direction of the association is negative.

Turning to the socioeconomic variables used in the analyses, both education and occupation were associated with the black-white mortality gap for women aged 15-44, while occupation was associated with the mortality gap for women between the ages of 45-64. When the analysis is performed for women aged 65 and over neither education, income, nor occupation were related to the black-white mortality gap. These findings suggest that among females, education and occupation played a role in reducing the black-white mortality gap, but only at the younger ages. Among males, none of the SES indicators played an important role in reducing the black-white mortality gap. There is one exception: education was associated with the black-white mortality gap for men over the age of 64. Thus, the socioeconomic factors analyzed in this study played only a modest role in explaining racial differences in mortality.

Discussion

Our analyses reveal that residential segregation is only modestly related to black-white differences in mortality, and that this pattern is most evident for males and females under age 45. Several limitations of the present study should be mentioned. First, mortality rates were not adjusted for census undercount which tends to bias upward the rates for African American males. Demographers have long indicated that the coverage of African American males in young adult and middle-age groups in U.S. decennial censuses is less complete than that of white Americans (Notes & Comments, 1994).

A second problem with these data is potential error linked to racial misclassification. In most cases, racial information in the census is obtained from one household member who provides information for not only himself, but for all household members. More importantly, racial information in the mortality records comes from death certificates. Funeral directors typically complete this information based on their own judgment. Massey (1980) found that 6% of self-

Table 5. Unstandardized Regression Coefficients for the Association of Segregation, Population Size and SES to the Black-White All-Cause Mortality Gap: Women

	(15-44)		(45-64)		(65-85+)	
	b	S.E.	b	S.E.	b	S.E.
Segregation	1.359*	(.619)	.271	2.161	-1.580	12.553
Pop. Size	-11.304	(8.807)	10.420	30.725	-84.410	178.515
Education Gap	3.583**	(1.220)	1.913	4.257	21.781	24.735
Income Gap	-6.96E-04	(.002)	.003	.006	-.038	.033
Occupation Gap	-2.973+	(1.756)	-13.401+	6.127	-38.685	35.600
Constant	136.772		96.992		869.725	
R^2	.103		.097		.091	
N = 107						

+=p<.10; *=p<.05; **=p<.01

Table 6. Unstandardized Regression Coefficients for the Association of Segregation, Population Size and SES to the Black-White All-Cause Mortality Gap: Men

	(15-44)		(45-64)		(65-85+)	
	b	S.E.	b	S.E.	b	S.E.
Segregation	4.513**	1.455	5.800	4.614	-48.460**	18.063
Pop. Size	-13.044	20.693	-72.898	65.609	274.207	256.869
Education Gap	3.701	2.867	-2.017	9.091	-82.182*	35.592
Income Gap	6.32E-04	.004	.002	.012	.034	.048
Occupation Gap	-5.443	4.127	-12.239	13.084	-38.836	51.226
Constant	92.366		1055.802		-341.551	
R^2	.111		.055		.162	
N = 107						

+=p<.10; *=p<.05; **=p<.01

identified African Americans were misclassified by their interviewer as white. Third, our aggregate analyses are subject to the "ecological fallacy" and our findings do not directly speak to the nature of the association between racism and health at the individual level.

The present analyses show an association between racial residential segregation and the black-white mortality disparity for ages 15-44 for men and women, even after SES factors are taken into account. This association between segregation and mortality could reflect the limited access to health enhancing resources that promote good health. Residential segregation may expose African Americans to a broad range of risk factors that increases their vulnerability to diseases. As a result of this exposure to bad living conditions, many African Americans may experience stress which in turn can affect physical and mental health. However, the underlying mechanisms and processes need to be identified and empirically verified.

Our findings here, though modest, point to the importance of understanding neighborhood effects on health status. One study examined the joint effects of income, social isolation, and depression on the risk of mortality using data from the Alameda County Study. Researchers found that individuals who were poor, socially isolated, and depressed were four times as likely to die than compared to individuals who were not (Berkman & Breslow 1983). Some researchers suggest that residential segregation is linked to high mortality levels simply as a result of low-SES characteristics. However, a study conducted by Haan and his colleagues (1987) documented that social and physical environmental factors are important contributors to the association between low-SES and high rates of mortality: residence in areas characterized by social and environmental deprivation (i.e., poverty areas) was associated with an increased risk of all-cause-mortality, even after adjusting for individual-level measures of SES and other traditional risk factors.

Our analyses reported here raise many questions and suggest that the association between segregation and health is a fruitful area for future research. We found that the black-white mortality gap among adults was higher in some cities than in others. Future research should examine regional variation in mortality across U.S. regions. Examining the relationship between segregation and mortality separately for blacks and whites and for specific major causes of death, including heart disease, stroke, and homicide is likely to shed important new light on the nature of the association. We plan to address these issues in future analyses. In addition, research is needed to explain the lack of an association between segregation and the black-white mortality gap for ages 45-64. Future research is also needed to identify the critical aspects of segregated neighborhoods that might be related to health and well-being. Understanding the effects of racism on health is crucial to assisting public health specialists to create effective programs, in cities where residential segregation is high, that would enhance the quality of life of African Americans and reduce their elevated rates of mortality.

[i] The terms African Americans and blacks are used interchangeably.

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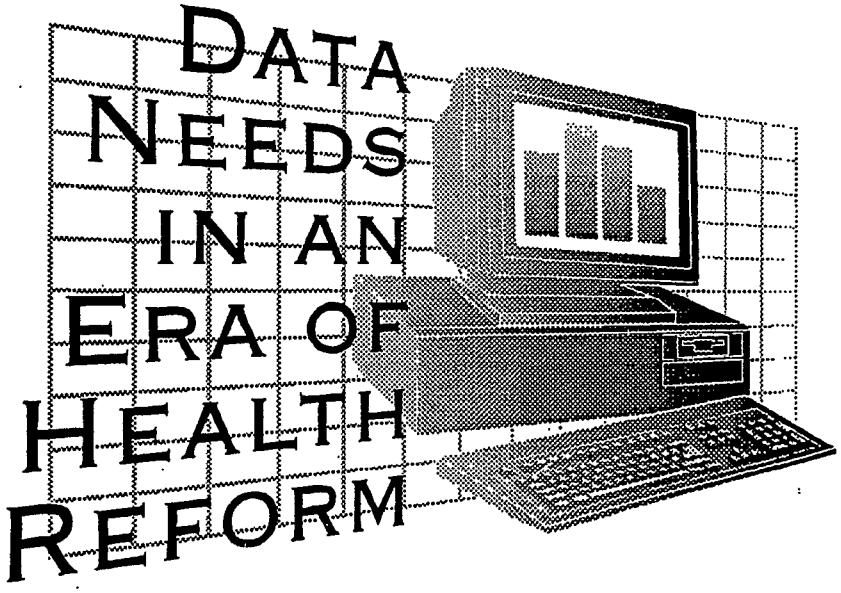
GENERAL DIFFUSION OF INNER CITY HEALTH PROBLEMS THROUGHOUT METROPOLITAN REGIONS

Roderick Wallace, Public Interest Scientific Consulting Service, Inc.

Paper not available for publication.

Session T

Monitoring Utilization of Health Care



MONITORING THE UTILIZATION OF HEALTH SERVICES BY MOTHERS AND CHILDREN IN A MEDICAID MANAGED CARE PROGRAM

Jay S. Buechner, PhD, Rhode Island Department of Health
Jane F. Griffin, MPH, MCH Evaluation, Inc.

The RIte Care Program. In August 1994, Rhode Island implemented a mandatory managed care program, RIte Care, under a research waiver from the Health Care Financing Administration. RIte Care covers an expanded population of low-income residents, including (1) AFDC recipients and "AFDC-like" families, who comprise a majority of persons covered by the state's Medicaid program, plus (2) an additional cohort of low-income, uninsured women and children, called the "waiver population." It does not cover other categories of Medicaid-eligible persons, such as the aged, blind, or disabled persons; foster children in the state's custody; or persons who become eligible because of large health care expenditures.

The transition of recipients from fee-for-service Medicaid has been phased in over a period of twelve months. On enrolling, RIte Care members join one of five private sector managed care plans organized on a "gatekeeper" model. At full enrollment, RIte Care will cover 75,000 persons, of whom 95 percent will be women of child-bearing age and dependent children. The waiver population is expected to total no more than 10,000 persons at full enrollment.

The five managed care plans participate in RIte Care through having been selected on the basis of their response to a request for proposals by the state. Of the five plans, one is a staff model health maintenance organization (HMO), three are independent practice association model HMO's, and one is an HMO established by the state's community health centers specifically to participate in the program. Except for the last-listed plan, all plans were serving commercial members in Rhode Island prior to the conception of RIte Care.

RIte Care members receive all the benefits available under fee-for-service Medicaid, plus a package of enhanced benefits developed for RIte Care and, for eligible mothers, family planning benefits for an additional 24 months post-partum. The enhanced benefits include transportation to and from health care providers' offices, smoking cessation sessions, childbirth education classes, parenting classes, and nutrition counseling. Almost all covered benefits are provided and/or paid for by the plans, who receive a monthly capitation payment for each of their RIte Care members. Selected benefits are carved out for payment on a fee-for-service basis, including all routine dental care and mental health and substance abuse treatment services beyond the "in-plan" maximum.

Research and Evaluation. RIte Care was designed jointly by the state's Medicaid and public health agencies with the intention of achieving improved health status as well as cost-effective coverage for high quality medical care. It includes a comprehensive research and evaluation (R&E) component, administered by the public health agency, that is integral to program administration. The R&E component will evaluate the impact of managed care on the health and health care of the covered population in four areas:

- Access to care
- Quality of care and health status
- Reform of the delivery system
- Benefit plan design

Within each area, a set of hypotheses have been established that will be tested during the research phase of the program. The research design developed to test these hypotheses specifies the measures to be monitored and the data sources to be accessed or established. This set of key indicators to be tracked includes the following measures of utilization for program participants:

- Measures of women's health
  - Number and timing of family planning visits
  - Cervical cancer screening per guidelines
  - Breast cancer screening per guidelines
- Pregnancy and birth indicators
  - Time of entry to prenatal care
  - Adequacy of prenatal care
  - Occurrence of mother's post-partum visit
  - Cesarean section rate
- Measures of children's health
  - Immunizations per schedule
  - EPSDT visits per schedule
  - Occurrence of preventive dental visits
- General measures of health
  - Frequency of inappropriate emergency room visits
  - Incidence of preventable hospitalizations
  - Continuity of primary care

These measures are available from a variety of existing data sources and from data collection activities instituted by the RIte Care program. New data collection efforts include (1) a periodic interview survey of low-income mothers, performed at their children's first birthday and linked to medical records; (2) complete person-level data from the five health plans on all medical encounters of RIte Care members; (3) review of selected medical records for focused studies; and (4) regular surveys of samples of RIte Care members. Existing data sources to be accessed include (1) the Medicaid Management Information System established for the fee-for-service program, (2) statewide birth certificates, and (3) statewide hospital discharge data. For some measures, more than one database must be accessed to provide data on the RIte Care population and data on a comparable population, either Medicaid recipients during the period prior to RIte Care or commercial members of the health plans participating in RIte Care.

Infant Health Survey. Of the new data collection efforts, the infant health survey and the health plan encounter data have required the largest efforts in development and implementation. The infant health survey is a face-to-face interview with a sample of women whose children have reached one year of age. The sample is selected from women living in 12 inner-city, low-income census tracts and includes both Medicaid eligible and other women. The survey content covers demographics, details of delivery, birth outcomes, regular providers of care, preventive and emergency utilization, health status, insurance coverage, and barriers to care. This information is also linked to data abstracted from the mother's and the child's medical records, as well as to the data filed with the child's birth certificate. The first infant health survey was a baseline survey conducted in 1994 and included 343 women whose children were born between March and July 1993; subsequent surveys are planned at two-year intervals.

Encounter Data System. At the core of the R&E component is the encounter-based utilization reporting system for RIte Care. The encounter data system consists of three distinct databases reported in common formats by all participating health plans:

- Person-level encounter data for all RIte Care members, including details of hospital inpatient stays, ambulatory care by all licensed providers, and expanded data on prenatal care and deliveries.
- Aggregated encounter data for all RIte Care members including utilization of ancillary services and gross measures of quality adapted from HEDIS, HCQUIS, and other sources relevant to managed care.
- Aggregated encounter data for a sample of each health plan's commercial members including data comparable to that submitted in aggregate for RIte Care members.

Data are submitted in quarterly batches, with the plans allowed 90 days to prepare the submission. All plans extract the encounter data from their internal claims or pseudo-claims databases, and the delay allows time for claims for services during a quarter to be submitted from providers and processed by the plans. The person-level encounter file includes information on member characteristics, provider characteristics, diagnoses, procedures, and charges and payments. The aggregate data file includes measures of utilization and quality. A comprehensive reporting system developed for use with the encounter database provides quarterly reports in the areas of financial and actuarial analysis, medical management, quality assurance, provider capacity, and reporting to HCFA, as well as research and evaluation. An ad hoc capacity has been established to support more detailed or unanticipated program needs for information.

Because the encounter data system involves the conversion of data from the idiosyncratic claims processing systems of five managed care plans into a common format, there have been many obstacles to overcome in the development process. Some key obstacles and their solutions are outlined briefly below:

Common Provider Identifiers. Each plan uses its own provider numbering system, and not all participating providers have, or are willing to obtain, an identification number as a provider in the fee-for-service Medicaid program. The solution is to use the state's license number as a common identifier, which has required the plans to obtain these numbers and link them to their provider records. Specific problems have arisen in the case of out-of-state providers and providers who bill through a corporate entity, such as a group practice.

Global Payment for Prenatal Care and Delivery. Most plans pay a single comprehensive fee to obstetricians that covers their services for prenatal care and delivery. The claim

that is submitted has no information on the number or timing of prenatal visits, the birthweight of the infant, the infant's gestational age, and other key information. In order to obtain this information, a simple birth worksheet to be filled out by the obstetrician was designed and adopted by all plans. Some plans are considering expanding use of the form to their commercial members in order to obtain uniform data on this subject for all their members.

Ambulatory Care Clinics in Teaching Hospitals. Several plans are using residents in hospital-based primary care teaching clinics to serve as members' "gatekeeper" primary care physicians. Claims submitted from these clinics do not identify the specific resident providing care. In order to look at issues of caseload, practice patterns, and continuity of care, the hospital clinics are providing additional data files of resident-specific encounters to the plans for submission to the RIte Care program.

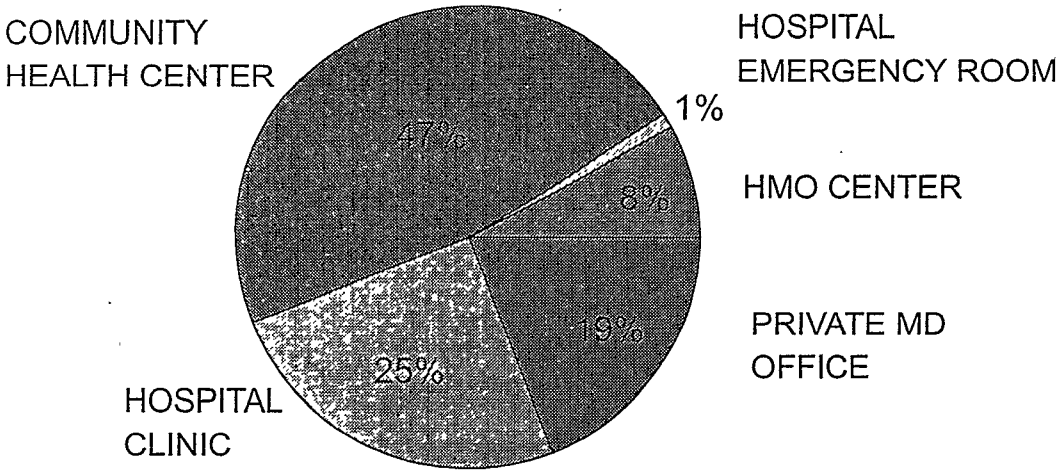
In each of the above instances, and in other design decisions not described, solutions were developed through collaboration between the program and the participating health plans. Consideration was given to the impact on the plans' resources as well as the need to meet key objectives of the program and the R&E component. In these deliberations, program staff assigned high priority to the inclusion of data relevant to issues such as provider accountability and emphasis on primary care and preventive services, as evidenced in the above examples.

Preliminary Findings. At present, the submission of encounter data from the plans is in the testing phase, with the first round of full reporting to be completed by September 30, 1995. Data from the baseline infant health survey has been analyzed, however, and several findings are worth presenting. Prior to the implementation of RIte Care, low-income infants in the sampled population were most likely (49 percent) to receive regular primary care at community health centers, followed by hospital outpatient clinics for pediatric or general medicine (25 percent) and private physicians' offices (19 percent). (See Figure 1.) Smaller numbers were seen in the staff model HMO's centers and hospital emergency rooms. Overall, a large majority of these infants were seen at a frequency judged adequate (57 percent) or better (28 percent), but a significant proportion (15 percent) had fewer than five visits during their first year of life. (See Figure 2.) Subsequent iterations of the infant health survey will provide information on whether the RIte Care program has changed and/or improved these utilization patterns.

Discussion. The introduction of managed care for Medicaid recipients presents challenges and opportunities that can only be monitored and assessed by the development and implementation of a program-oriented evaluation plan. The availability of data is a critical determinant of the scope of the evaluation plan, and the adequacy of existing data sources and the capacity to support the development of new sources must be realistically evaluated in developing such a plan. The ability and willingness of key partners, such as the managed care health plans in the RIte Care program, to collect and submit uniform data must be determined and, if necessary, enhanced through contract provisions, collaborative relationships, and mutual acceptance of the importance of evaluation for such programs.

FIGURE 1

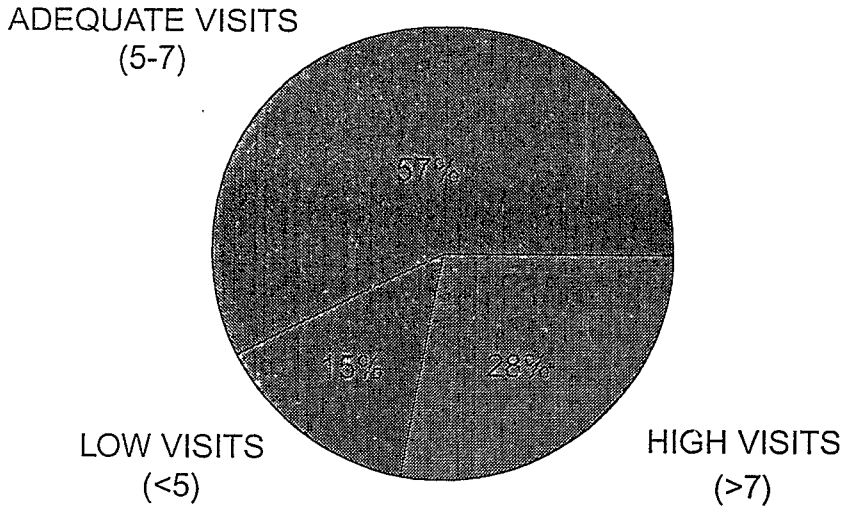
REGULAR SOURCE OF PRIMARY CARE, BIRTH TO AGE ONE, 1993-1994



N=343

FIGURE 2

ADEQUACY OF PEDIATRIC CARE IN THE FIRST YEAR OF LIFE



N=343

MONITORING RISK AND IMPACTING UTILIZATION OF PERINATAL CARE BY VULNERABLE POPULATIONS

Dawn K. Aldridge, Los Angeles County Department of Health Services
Miriam Schocken, J. Robert Bragonier, Ann Petrus-Baker

INTRODUCTION

Perinatal risk assessment is designed to enable clinicians to anticipate and attempt to prevent adverse birth outcomes such as preterm birth, low birthweight, morbidity, and mortality. Several standardized prenatal risk assessment and record keeping systems have been developed to enable physicians to efficiently assess risk, maintain a centralized and concise patient record, and design appropriate care plans. Standardized systems such as POPRAS (Problem Oriented Perinatal Risk Assessment System), the Hollister Prenatal Module, Bibbero Systems, and the ACOG Antepartum Record are designed to be used in medical offices for clients who are already utilizing care (Gollin, 1990). These systems tend to be heavily medically oriented, technical, and long.

Comprehensive risk assessment and prenatal care is frequently inaccessible to women who would most benefit from the medical care and support of health care providers. Some of the most vulnerable and hardest to reach women do not have access to medical and social services and may be unaware of their risks in pregnancy. These women are not assessed appropriately for pregnancy risk. They also may experience psychosocial and economic problems that lead to stress and medical problems in pregnancy, resulting in poor outcomes. Public health perinatal programs bear the responsibility of reaching, assessing, and caring for these women before it is too late to try to improve their outcomes.

The primary goal of the Los Angeles County Department of Health Services Comprehensive Perinatal Outreach Program (CPOP) is to outreach to the most vulnerable, hardest to reach women, to assess their risks in order to encourage and facilitate appropriate care plans through case management. CPOP defines vulnerable and hard to reach pregnant women as women who lack basic needs including medical care, social support, shelter, food, and transportation; women who may be experiencing domestic violence, emotional problems, mental disabilities, or highly stressful life events; and, women who are substance abusers or who are under the age of sixteen.

Key components of CPOP's outreach and case management process are risk screening during outreach and risk assessment during case management. While lengthy and complex standardized systems are inappropriate in an outreach setting, lessons learned from research on standardized indices were invaluable in the development of our own risk screening and assessment tools. We have modified and combined elements from existing assessment systems to suit the needs of our clients, field staff, and research staff. We have transformed individually oriented risk assessment into a screening system that may be used to measure population based needs and characteristics as well as individual client needs and risks. While we utilize our system to determine whether a client meets our high risk criteria, we also utilize our data to describe the demographics of our population, assess the population's utilization of and access to health care, improve targeting of our interventions, and analyze outcomes and program effectiveness.

PROGRAM DEVELOPMENT

Due to time constraints we were forced to develop our policies and procedures and our data collection tools while staff were in the field. We found that the most pragmatic way to accomplish this task was to collapse the development of our outreach and case management protocol into the forms development process. During this time we created outreach and case management procedures, high risk criteria for case management (see appendix A), and all of the forms necessary to implement the procedures and collect data. The procedures, criteria, and forms were developed and refined through many staff meetings including heads from all disciplines: health education, nursing, obstetrics, social work, nutrition and program evaluation. Although this situation was less than ideal, as we developed our forms we were able to refine our purpose, define how our multidisciplinary teams would collaborate, and create necessary links with other community agencies and county health centers.

All CPOP contacts begin with an initial client encounter. Some encounters are obtained through referral from the CPOP toll-free pregnancy hotline, public agencies, public health clinics such as high risk obstetrical or teen clinics, or community based organizations. Many clients are located through direct outreach in public venues. Most of our outreach efforts are targeted to areas in Los Angeles County that have the highest rates and/or numbers of infant deaths and low birth weight births.

Upon contact with a prospective client, a community health worker conducts an initial screening. The worker identifies pregnant or postpartum clients who appear to be at risk and/or who may not be receiving adequate care. If the client exhibits any risk factors she is referred to a public health nurse for formal risk assessment and possible case management intake. Referrals for health and social services are given to women who are not candidates for or who decline referrals to case management assessment. Health education materials are also distributed.

The public health nurse interviews each potential case management client, assesses her risk level, and decides whether or not she will be case managed based on CPOP's high risk criteria and the nurse's professional judgement. Once a client is enrolled in case management,

she is referred to a prenatal care provider and to other CPOP services as needed, including health education, nutrition or social work intervention. The nurse develops a care plan, follows up with the client, and notes her progress in her file. The public health nurse and the community health worker attempt to contact each woman at least twice per month.

Within a few weeks after the case managed client delivers her infant, a postpartum evaluation is completed. Clients who need guidance in the postpartum period may be retained in case management for one year. Occasionally, new clients are enrolled in the postpartum period. Decisions to retain previous clients or enroll new postpartum clients are based on case management criteria for postpartum clients. All postpartum clients are provided with referrals for pediatric care, family planning, and special needs.

FORMS DEVELOPMENT

CPOP's forms development process was inexorably linked to protocol, procedure, and case management criteria development. As we created forms we were in essence creating policy; therefore, a great deal of research and time went into designing our forms. Our goals were to produce forms that would guide staff through the outreach and case management process that were easy to use and not burdensome to clients. Yet, they needed to be comprehensive enough to enable us to assess risk, describe our population, and evaluate the impact of our program on birth outcomes and patient behavior.

We drew upon many resources in developing our forms, including literature regarding the impact of specific birth outcome indicators, clinical experience, experience of other perinatal programs, and outreach field experience. Although we field tested and revised before the first printing, all of our forms were dramatically revised after one year of field use.

The Outreach and Referral Form

At each outreach encounter, a community health worker screens prospective clients using the Outreach and Referral Form. This form was the most difficult to design because perinatal outreach was a relatively new approach for us. We lacked sample forms to guide us. In addition, the form was difficult to organize because it was to serve multiple purposes. The outreach and referral form serves as an encounter script for community health workers and a guide for making referrals, as well as a preliminary risk screening and data collection tool. This form was revised several times during its initial development in order to make it more user friendly. Feedback was solicited from field staff as they gained field experience using the form. After the first year we condensed the long seven page form to a more manageable five pages.

The form includes seven sections: enrollment, pregnancy status, health care referral, financial assistance, needs assessment, risk assessment, and actions taken. Instructions to staff are imbedded in many sections of the form. This structure enables the community health worker to provide referrals to clients throughout the form within the context of the needs being discussed while collecting data for analysis.

At enrollment demographic information and the source of the contact is collected. Then, the client's pregnancy status is established. Referrals to needed prenatal care, postpartum care, or pregnancy testing are given as indicated. Next, the community health worker determines whether the client needs and is eligible for Medicaid. The client is asked about her health and personal needs. Based on her stated needs, referrals to services such as family planning, health education, immunizations, and well baby care, together with health promotion material, are provided. Finally, the community health worker conducts a preliminary risk screening which was abstracted from our case management enrollment criteria. Clients who exhibit at least one risk factor are referred to a public health nurse for further evaluation. After the interview is completed the health worker notes all types of referrals, information, and assistance he or she provided in the "actions taken" section.

The outreach and referral form gives us a broad picture of the characteristics of the women that our community health workers interview. The data include information about all of the women that we contact, including those who refuse our services. Thus, we are able to determine who we are reaching and how well we are reaching the high risk population within the target area. We also use the data to determine the sources of contact that yield the most high risk women and potential case management clients. We use this information to target our outreach efforts more effectively. In addition, we utilize the data to characterize the most common needs and risks of our population. This information improves our ability to meet the needs of our target group. Finally, supervisors use outreach case load information to identify staff work patterns and to provide statistics for official reports.

Case Management Intake Form

A public health nurse collects more detailed information about demographics, utilization of care, and risks on the Case Management Intake Form during the case management intake process. While the outreach form is designed for risk screening and referral, the case management intake form is designed for formal risk assessment. Also, the intake form was designed to be linked to the Birth Outcome Form so that we could compare outcomes, such as birthweight and gestational age, across risk levels and demographic categories.

The case management intake form begins with demographic questions. We included factors that we considered to be possible indicators of poor outcomes in our population such as age, ethnicity, relationship with the father, education, type of residence, and health insurance status. We were interested in assessing the level of vulnerability in our population by using these indicators and in comparing outcomes across these levels.

Education, type of residence, and employment and insurance status are seen as proxies for income or financial vulnerability. The status of the woman's relationship to the father may indicate her level of social vulnerability.

We also asked the patient about her entry into prenatal care and her estimated date of delivery. We wanted to be able to ascertain when in pregnancy we were obtaining patients, and whether they were already in prenatal care. We anticipated that many of our clients would not yet have begun prenatal care. In fact, we hoped to obtain as many case management patients as possible who were not receiving care. In order to help us understand the needs of our clientele better, we asked clients who were not getting prenatal care why they had not received care. We provided fifteen possible barriers as options as well as an "other" category. We based these possible barriers to prenatal care upon current literature and clinical experience. (Scupholme, et al., 1989; Lia-Hoagberg, et al., 1990; Cartwright, et al., 1993; Aved, et al., 1993; Driscoll, et al., 1990; Giblin, et al., 1990; Hansel, 1989; St. Clair, et al., 1990; Harvey and Faber, 1993; Leatherman, et al., 1990; Sable, et al., 1990) We also planned to share this information with the public health clinic administration, hospital and clinics committee, and the OB Access Task Force, so that they could improve services to low income, high risk patients.

The risk assessment portion of the case management intake form has a two-fold purpose: to assess the client's risk for poor birth outcome and to assess the client's risk for not obtaining prenatal care. CPOP has a clearly delineated target group: women who are hard-to-reach, who are socially and psychologically vulnerable, and who are at high risk for poor birth outcomes. Therefore, it was critical that we determine both the patient's direct risks for poor birth outcome as well as her need for personalized support and case management. The latter goal was based on the assumption that clients who have more psychosocial risks may be less able to obtain adequate prenatal care, tend to enter care later, and may have medical and social needs that go unattended.

With these dual goals in mind we ruled out the use of any single standardized risk assessment form because standardized forms are not designed for use in outreach setting and they tend not to assess the risks of women with complex psycho-social needs. Baruffi, Strobino, and Dellinger (1984) found that the predictive ability of standardized risk scales varied significantly across two populations of women who were socio-economically similar, despite controls for population fixed effects. Molfese (1989) suggested that more work should be done to determine if risk scales tailored to specific communities yield better results than generalized risk scales. In light of the doubts generated by these validity studies, we felt that it was necessary for us to tailor our risk scale to our target population.

We began by gathering information on risk assessment criteria and risk scales. We reviewed prospective standardized scales including the ACOG Antepartum Record and the Problem Oriented Perinatal Risk Assessment System (POPRAS, 1987). We also considered several tools developed by local public health and community based perinatal programs. In addition, we reviewed literature pertinent to preterm risk, medical risk and psychosocial risk (Holbrook, Laros, and Creasy, 1989; Bragonier, Cushner, Hobel, 1984; Lobel, Dunkel-Schetter, and Scrimshaw, 1992). Finally, we drew upon the clinical experience of three obstetrician/gynecologists, a clinical social worker, and several public health nurses.

The first iteration of the intake form was long and complex. We quickly found that it was too cumbersome for our public health nurses to use efficiently. Based upon field experience and further research, we greatly modified the form and ultimately defined three categories of pregnancy risk including: preterm risk, medical problems, and psychosocial risk.

While developing our preterm birth high risk criteria, we determined that a partially weighted, simple method of assessing clients for our high risk case management program and the use of a limited list of risk factors would be most effective. We based this decision on the work of Holbrook, Laros and Creasy (1989) who found that there was no predictive advantage gained in using a complex system of risk scoring. They concluded that inclusion in a high risk group based on the presence of any one major risk factor or any two minor risk factors was as sensitive as inclusion based on an additive risk score. They compiled a list of the most highly correlated risk factors in their sample to create their "Major and Minor Risk Factors of the Modified Scoring System for Spontaneous Preterm Labor." CPOP adopted these factors for the preterm risk criteria and adopted a bimodal approach to inclusion of clients into the high risk case management program. Any client who exhibits any one of the major risk criteria, or two minor factors as defined by Holbrook, Laros, and Creasy, is considered high risk for preterm birth and qualifies for case management. We collapsed several sets of questions from POPRAS into single questions to define the major risks for the medical problems section of our current intake form. Any positive answer qualified the woman for case management services.

Each risk included in the psychosocial section of the intake form also was considered a major risk. This approach enabled us to admit clients who were psychosocially vulnerable, but who did not show any current medical risk or problems. Research concerning the impact of psychosocial stressors and perceived stressors on birth outcomes supports our definition of these stressors as criteria for case management (Bragonier, Cushner, Hobel, 1984; Lobel, Dunkel-Schetter, and Scrimshaw, 1992). In addition, based upon research regarding barriers to care, we knew that psychosocial risk is negatively related to timeliness of care, and, thus, could be negatively related to birth outcomes (Sable, et al., 1990). The data from this section also help us to describe and better understand the women we are serving and to determine the relationship between psychosocial risks and birth outcomes in our population.

After our first year of operation we revised our original form, shortening it from four pages to two pages. We held discussions with field staff who were using the form, with evaluators who were using the data for analysis, and with data entry personnel. Tradeoffs between research goals and the outreach process were made in shortening the form and collapsing several questions on individual risks into a single question regarding sets of risks. A more complex intake form could yield a more exact picture of the individual risks of each client and might enable us to estimate impacts of particular medical or preterm risks in our populations. However, in the outreach setting, it is frequently difficult to obtain specific information from clients on each of several medical conditions. The short case management intake form is a more useful tool for determining whether or not a client should be classified as high risk. We opted for this efficient, user friendly solution. Meanwhile, we also identified and modified survey questions that were ambiguous or difficult to understand.

ANALYSIS

Sample

This sample includes 377 CPOP case managed clients who delivered within the period of September 1994 to April, 1995. Women who had a multiple gestation or for whom we did not have birthweight information available were excluded from this analysis. Since CPOP is not primarily a research project, we were not able to conduct a formal case control study, nor do we have complete demographic records for each client.

Our sample is predominantly Hispanic (58%), 26% were African-American, 6% were Caucasian, 7% were Asian/Pacific Islander, and 3% were of other ethnicities. A large majority (85%) reported that they were insured by Medicaid, while just 3% had private health insurance and 12% percent had no health insurance. Just over one quarter (28%) reported that they were married, 67% were never married, and 5% were divorced/separated/widowed. Under half (47%) lived with their partner. Fourteen percent of the clients reported that they had less than a sixth grade level of formal education, 72% said they had schooling between 6th and 12th grade, and 14% had studied beyond high school. A large majority (86%) were unemployed, 6% were employed full time, and 8% were employed part time. Nine percent of our clients were under the age of sixteen, 28% were aged 16 to 19, 45% were aged 20 to 30, and 18% were over 30 years of age.

Most clients (82%) had seen a doctor during the pregnancy by the time of case management intake, while 18% had not seen a doctor before intake. All clients who did not have any prenatal care at intake were referred immediately for care and entered within a month of intake. We lack information on the trimester of entry into prenatal care for 70 clients and the number of prenatal care visits for 50 clients. Of those for whom we have information, 46% entered care in the first trimester, 34% in the second trimester, and 21% in the third trimester. Thirty-three percent had received over 13 prenatal care visits at the time of delivery, 37% had 10 to 13 visits, 23% had 6 to 9, and 8% had fewer than six visits. Few cases (4%) entered case management in the first trimester of pregnancy, 53% entered some time in the second trimester, and 43% entered in the third trimester.

Methods

For entry into case management, each client must have exhibited at least one risk, however, most of CPOP's clients exhibited several risks. We want to know if the level of risk within our high risk group is related to birthweight and prenatal care utilization. We compare the mean risk level of our clients across categories of birth outcome and prenatal care utilization using our prenatal risk index. Birthweight categories include high (>4000gms), normal (2500-4000gms), low birthweight (1500-2499gms) and very low birthweight (<1500gms). We also compare mean birthweight in grams across levels of prenatal care adequacy to determine whether adequacy of care is linked to birth outcome in our sample. We utilize ANOVA means test or Kruskal-Wallis One-Way ANOVA. All ANOVA results are tested for equal variances across categories as well as for normality. Where ANOVA conditions for the homogeneity of variance across categories are not met, Kruskal-Wallis statistics are employed rather than the F-statistic.

The prenatal risk index is based upon our case management high risk criteria. The prenatal risk index employs an additive scoring of risks where the weight of each major risk is one, and each minor preterm risk as defined by Holbrook, Laros and Creasy (1989) counts as half of a major risk. We chose a simple additive score of total risks rather than a complex weighted score for several reasons: a) empirical correlations are not available for weighting the impact of all of our risks; b) when reliable empirical evidence is not available, weights tend to be arbitrary; a) weighted scales do not necessarily predict outcomes better than unweighted scales; and, d) an unweighted risk score is simpler and more cost effective to calculate (Strobino and Baruffi, 1984; Molfese, 1989). Our prenatal risk index has a serious limitation in that most risks are self reported at the time of intake. Reporting of medical and preterm risks require testing or clients knowledge of specific medical information. These risks are most likely under-reported. We have more confidence in the self-reported psychosocial risks. All CPOP clients on average reported a total of 2.75 risks, .25 preterm risks, .86 medical risks, and 1.65 psychosocial risks.

The Kotelchuck index was chosen as our measure of adequacy of prenatal care because it evaluates on the basis of two distinct criteria: timing of the initiation of prenatal care and adequacy of received services (Kotelchuck, 1994). A modified version of Kotelchuck's Adequacy of Prenatal Care Utilization Index was developed for this study with the help of Becky Yano, PhD, and in consultation with Dr. Kotelchuck. We needed to modify Kotelchuck's tables because his index requires the information on the month of pregnancy that

prenatal care began. CPOP only collects information concerning the trimester that prenatal care began.

CPOP was not designed to be a research project; therefore, we do not have a control group for this research. However, we utilize small area analysis to compare our outcomes to relatively lower risk populations. In our small area analysis we compare our birthweight outcomes and prenatal care utilization to overall Los Angeles County statistics and national statistics, County statistics are provided by the Data Collection and Analysis Unit of the Department of Health Services of Los Angeles County. National statistics are taken from the Centers for Disease Control and Prevention 1992 Advance Reports. These are the most recent statistics currently available.

Risk, Prenatal Care Utilization, and Outcomes

We were able to calculate the modified Kotelchuck Adequacy of Prenatal Care Utilization Index (APNCU) for 307 women in our CPOP sample. Of these 29% of CPOP clients had inadequate prenatal care, 2% had intermediate care, 69% had adequate or adequate plus care. Adequacy of care differed greatly between the two largest ethnic groups of our sample: 45% of African Americans had inadequate care compared to 23% of non-African-Americans. This difference is statistically significant ($p<.001$). We also found that inadequacy of care was most common for women under the age of 16 (40%) and over 35 (41%), while 28% of women 16-19, 27% of women aged 20-30, and 18% of women 31-35 received inadequate care.

Using ANOVA, we found that total risk level and psychosocial risk level were both significantly related to adequacy of prenatal care. Women who had inadequate care on the APNCU index average 3.3 total risks while women with adequate or adequate plus care averaged 2.6 total risks ($p<.001$). Women with inadequate care also averaged 2.0 psychosocial risks while women with at least adequate care averaged 1.5 psychosocial risks ($p=.002$). However, differences in the mean birthweight did not vary significant over level of prenatal care adequacy.

We also found that the mean total risk level of the client does not significantly differ across groupings of birthweight. The total risk level was broken down into categories of risk; preterm, medical, and psychosocial. The means of these risk levels also do not differ significantly across birthweight categories.

Comparisons

Since our sample contains a solely high risk population, it may be considered higher risk for poor birth outcomes than the national and the county samples. CPOP's clients tend to enter care much later than most pregnant women in the nation or in the county. While 21% of CPOP's clients entered care in the third trimester, only 5.2% of women in the United States and 3.4% of the women in Los Angeles County entered care in the third trimester or not at all. Over 75% of pregnant women in the county and in the nation initiated care in the first trimester, while 46% of CPOP's sample began care that early. CPOP's overall low birthweight (LBW) rate of 9.3% (<2500 grams) is higher than in both the county (6.1%) and the nation (7.1%). African-Americans experience much higher LBW rates than other ethnic groups both nationally and in the county. African Americans make up a larger percentage (26%) of CPOP's sample than of the national sample (17%), or the county sample (11%). African-Americans experience a LBW rate of 13.3% nationally and 12.5% in the county. The LBW rate of African-American CPOP clients is comparable at 13.5%. The larger size of CPOP's African-American sample draws CPOP's low birthweight rate upward. CPOP's very low birthweight (VLBW, <1500gms) rate compares more favorably to national and county statistics. CPOP's VLBW rate is .8%, the national VLBW rate is 1.3% and the county rate is 1.1%.

Discussion

In developing CPOP's case criteria, we posited that psychosocial risk would predict the level of the adequacy of prenatal care. Through this analysis we were able to confirm this assumption. Our outreach and referral screening forms and our case management intake form enable us to determine level of psychosocial risk and to enroll vulnerable clients, who are frequently not accessing care, even if they do not exhibit medically related risks.

We are unable to establish a significant link between the level of risk or the level of prenatal care adequacy and the birthweight outcome within our sample. This is largely because all our clients were high risk and our sample lacked the variation necessary to make significant comparisons. Therefore, we compared our high risk sample to the lower risk national and county populations who rarely received late care. We found that although our clients had continuous case management their outcomes were still somewhat worse than County and National levels. However, our African-American clients compared favorably to national and county statistics. Although we cannot make any definitive judgement on the cause of increased low birth weight in the CPOP sample, it appears that a major factor may be adequacy of prenatal care.

A major value of this study is that CPOP, a public health outreach and case management program, was able utilize public health nurses in the field to collect data from a population that is costly to reach and, therefore, costly to study. A more formal case controlled sample should be performed in order to establish more firmly the link between lack of access to care and risk to outcomes.

APPENDIX A: Case Management Protocol
CRITERION 1: At Risk For Preterm Birth
MAJOR FACTORS (One or more of the following)

A. History of : preterm labor or delivery, DES exposure, 2nd trimester abortions (2 or more), cone biopsy, or uterine anomaly

B. Current problems:
cervix effaced < 1 cm. long (<34 wks),
cervix dilated > 1cm. internal os (<34 wks),
abdominal surgery > 18 weeks or cerclage,
uterine irritability < 34 weeks,
polyhydramnios, or multiple gestation

C. Street drug use this pregnancy
D. Alcohol use this pregnancy

MINOR FACTORS (Two or more factors):
A. 2nd trimester abortions (1 or more)
B. 1st trimester abortions (3 or more)
C. Bleeding > 12 weeks this pregnancy
D. Febrile illness during this pregnancy
E. Pyelonephritis this pregnancy
F. Environmental tobacco smoke exposure

CRITERION 2: Medical Problems During Pregnancy
A. Class A2 diabetic or higher
B. History or presence of hypertension; presence of preeclampsia, or toxemia
C. Asthma
D. Sero-positive for HIV
E. Smoking
F. Anemia (less than 11g/dl)
G. Nutritional Deficit: obese/underweight prior to pregnancy, insufficient/excessive weight gain, weight loss currently, pregnant less than one year ago, experiencing excessive nausea/ vomiting, inadequate diet, or pica

CRITERION 3: Psycho-Social Risk Factors
A. Homeless
B. Mental illness or severe depression
C. Age less than 16
D. A major stressful life event: death or severe illness in family, immigration, change in marital/partner status, severe marital discord, severe ambivalence about pregnancy
E. Severe socioeconomic hardship
F. Confirmed or suspected family violence
G. Lack of adequate support system
H. Noncompliance with prenatal care appointments
I. Inadequate, unclean or unsafe living enviroment

CRITERION 4: Postpartum Risk Factors
A. Any drug or alcohol use by client if breastfeeding, OR history of alcohol/drug abuse by client or other household member.
B. Current tobacco use by client
C. Preterm infant (born less than or equal to 36 weeks gestation)
D. Infant requiring 2 or more monthly health related visits
E. No prenatal care prior to third trimester
F. Client with emotional, intellectual, and/or physical limitations or lack of parenting skills.
G. Current family violence (may include child abuse)
H. Lack of family / social support system
I. Inadequate, unclean or unsafe living environment
J. Age under 18, with 2 or more children
K. Current tobacco use by other household member

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VARIATION AMONG STATES IN THE USE OF PREVENTIVE HEALTH SERVICES AND HEALTH INSURANCE COVERAGE

Emma L. Frazier, Centers for Disease Control and Prevention
Nagi Salem, Minnesota Department of Health
Catherine A. Okoro, Centers for Disease Control and Prevention

In 1992, an estimated 38.5 million Americans under the age of 65 years did not have health care coverage (1). Many Americans thus do not receive health care for acute medical problems or preventive health care. Thus, it is essential to have state-specific information for tracking health insurance coverage and the use of preventive health services.

As states mount efforts to expand health care coverage, understanding the sociodemographic and economic characteristics of the uninsured, particularly as they pertain to preventive health care, is crucial to developing effective reforms of public health care. Understanding the degree of variation of the uninsured among states will provide data critical to develop baseline state-specific data that should be of value in monitoring health care coverage, as well as allocation of resources. In addition, investigation of reasons for the variation of uninsured persons among states is critical to public health professionals as more states consider their own efforts in health care reform.

This report summarizes state-specific data from the 1993 Behavioral Risk Factor Surveillance System (BRFSS) for persons aged 18-64 years regarding the status of health insurance for acute care, the receipt of preventive services, and selected behavioral risk factors. The primary objectives of these analyses are to: a) present state specific BRFSS measures of the uninsured and attempt to explain the reasons for variation in health insurance coverage among the states; b)assess the variation of demographic characteristics, risk behaviors, and the use of preventive health services among uninsured and insured adults; and c) highlight analysis of supplemental questions added to the BRFSS in Minnesota to address health care utilization and source of health care coverage.

METHODS

The BRFSS is a state-based, random-digit-dialed telephone surveillance system. All states select a probability sample of adults aged ≥ 18 years (2). To obtain this sample, most states use a multistage cluster design. In 1993, 49 states and the District of Columbia participated in the BRFSS, with each state completing from about 100 to more than 400 interviews per month.

We used responses from the BRFSS questionnaire that ascertained if a person had health care coverage. Each person interviewed was asked "Do you have any kind of health care coverage, including health insurance, prepaid plans such as HMOs (Health Maintenance Organizations), or government plans such as Medicare?". Other questions from the BRFSS ascertained demographic characteristics, the use of preventive health services, health status, and drinking and smoking status. In addition, state added questions added to the Minnesota BRFSS are discussed. To assess the validity of these data, we compared data from the Current Population Survey (CPS) (1) and the BRFSS.

To identify the relationship between insurance status and economic characteristics, we examined state-specific measures of economic deprivation such as employment rate, less than a high school education, living below the poverty level, and low per capita income (3). We also calculated the prevalence ratio (ratio of prevalence among the uninsured relative to the insured) for use of selected preventive health services, self-reported health status, and selected health risk behaviors.

All sample estimates from the BRFSS were statistically weighted to reflect the civilian population in each state. We used SESUDAAN to calculate standard errors for the state-based estimates.

RESULTS

The number of completed interviews among all states ranged from 1,189 to 4,361. The number of men ranged from 493 to 1,771; and the number of women ranged from 696 to 2,590 among the states. The mean response rate (calculated as number of persons who completed

interviews / the number of people who were eligible for interview) ranged from 63% to 96% among all states.

The percentage of persons who reported having no health care coverage varied widely across the states, from less than 10% in two states: Hawaii (7%) and Minnesota (9%) to more than 20% in Florida (21%),California (21%), Nevada (22%),Oklahoma (22%), Texas (23%), New Mexico (24%), and Louisiana (26%)(Table 1). Using Pearson's correlation coefficient, we found a significant correlation between the state-specific data of the BRFSS and the CPS ($r=0.71$, $p<=0.05$) (Figure 1). In addition, Figure 1 shows the plot of the paired estimates and a regression line between the estimates.

Limited by the availability of data, we defined vulnerable subgroups as those groups of persons at increased risk of not having health care coverage. These person may include those of minority/ethnic groups, those with low family income (less than $20,000 per year), those with less than a high school education, unemployed persons, and younger persons (under 30 years old). We identified 18 states with at least 10% Black residents and 7 states with at least 10% Hispanic residents. Among those states, the percentage of uninsured Black persons ranged from 11%(±9) in New Jersey to 35%(±6) in Louisiana; the percent of uninsured Hispanic persons ranged from 25%(±5) in Florida to 40%(±5) in Texas. Blacks were as much as two times more likely and Hispanics were three times more likely than Whites to be uninsured (Table 2).

Younger persons were more likely than persons aged 30 years and older to report being uninsured. The percentage of uninsured among persons under age 30 ranged from 12%(±4) in the District of Columbia to 34%(±7) in New Mexico. Persons with less than a high school education were up to three times more likely than persons with at least a high school education to be uninsured and ranged from 14%(±8)in Hawaii to 56%(±7)in Texas. Persons with a family income less than $20,000 per year were at up to five times more likely than those with more than $20,000 per year income to report being uninsured and ranged from 12%(±4) in Hawaii to 48%(±6) in New Mexico. Unemployed persons were up to six times more likely than employed persons to report being uninsured. The prevalence of uninsured among the unemployed ranged from 21%(±10) in Massachusetts to 70%(±13) in Arkansas.

We found a significant positive association between the prevalence of being uninsured and the economic variables of unemployment ($r=.37$, $p<.01$), being at or under the poverty level ($r=.57$; $p<.01$), and having less than a high school education ($r=.30$; $p=.03$). In addition, we found a significant negative association between the prevalence of being uninsured and per capita income ($r=-0.50$; $p<.01$).

Among the states, uninsured persons aged 18-64 years were 40%-70% less likely than insured persons to have had their blood cholesterol checked in the past 2 years. Prevalence rates for the uninsured ranged from 24%(±9) in Ohio to 40%(±9) in Connecticut. Uninsured persons aged 40-64 years were 30%-90% less likely than insured persons to report having had a digital rectal examination in the past 2 years and ranged from 10%(±9) in Arizona to 47%(±17) in Wisconsin. Uninsured women aged 40-64 years were 30%-90% less likely than insured women to report have had a mammogram and a clinical breast examination in the past 2 years, ranging from 14%(±12) in Utah to 66%(±18) in Connecticut. There were small variations in the use of Pap smear among insured and uninsured women (Table 3).

Significant differences existed between the self-reported percent of fair or poor health among the insured and uninsured. Among the uninsured, persons were up to three times more likely than insured persons to report being in fair or poor health, ranging from 8%(±5) in Alaska to 23%(±5)in West Virginia (Table 1). The uninsured were at most 8 times more likely than the insured to report that they couldn't afford to see the doctor when needed to due to cost, ranging from 28%(±6) in Vermont to 53% (±10) in New Jersey.

Reported current smoking and binge drinking were at most 2 times more likely among the uninsured than among the insured. Uninsured persons reported current smoking ranging from 27% (±5) in California to 48% (±10) in Massachusetts. Binge drinking among the uninsured ranged from 7%(±3) in Tennessee to 38%(±9) in Rhode Island.

Minnesota State-Specific Data

The Minnesota Department of Health asked all BRFSS respondents 12 supplemental questions about health care utilization and insurance coverage. Employed persons were asked a question to determine their occupational status. Among insured Minnesotans, 75%(±2) reported that their primary source of coverage for health insurance was from their employer. Employment status seems to be a determinant as to whether a person is covered by health insurance or not. While 9% of all adults age 18-64 are uninsured, the percentages for those employed for wages, self-employed, and unemployed were 7%, 21%, and 28%, respectively. The highest percent of the uninsured by occupational group were among those reporting their occupations as service occupations (20%). Examples of service occupations include food service, child care, etc. The second highest were those classified in the craft occupation group (17%), e.g., mechanics, repairers, and construction trade workers. Only 4% of managers and professionals reported being uninsured. The percentages of insured employed persons in other occupational groups were technical, sales administrative support (6%); farming (15%); and laborers (10%).

Among Minnesotans, 44% of the uninsured, but only 21% of the insured reported no visits to a physician in the past year. Similarly, 46% of the uninsured, but only 21% of the insured reported no visits to a dentist in the past year. However, the magnitude of difference in the rate of hospitalization among the insured and the uninsured was much smaller, 9% for the insured versus 8% for the uninsured adults.

DISCUSSION

The percentage of people who are uninsured varies widely among the states, from 7% to 26%. Among the states, the uninsured are more likely to be in fair or poor health, younger, less educated, of minority/ethnic groups, unemployed, and live in families with lower incomes. Moreover, these persons are less likely to engage in preventive health practices that can be effectively encouraged in the primary health care setting. Because lack of insurance is associated with limited access to important preventive health services, successful health care reform at the state level may ultimately lead to improvements of access to preventive health services.

Contributing factors to the variation in health insurance coverage across regions of the country are between-state variability in unemployment rates, per capita income, percent of those with low educational attainment, and percent of those living below the poverty level. This variability has been demonstrated in our study by the strong correlations between these factors and state-specific estimates data on characteristics of uninsured persons. Our findings support earlier studies that have found lack of health care coverage to be associated with the use of fewer medical services and shows some of the variability across the US (4-6).

Information derived from state-specific questions added to Minnesota's BRFSS can be valuable in helping the state improve health insurance coverage for its uninsured population. For example, the state-specific data from Minnesota show that although most persons are insured through employer plans, certain categories of employed and self-employed individuals, e.g., service and crafts occupational group members find it difficult to obtain health insurance coverage.

The findings of this report are subject to at least three limitations. First, because the BRFSS includes only households with a telephone, the findings may underestimate the prevalence of being uninsured among persons not residing in households with telephones (e.g., persons living below poverty level, less educated persons, and the unemployed). Furthermore, nonrespondents to the BRFSS tend to be younger and less educated persons, who would have an increased likelihood of being uninsured. Third, estimates are based on self-reported data with all the inherent limitations in surveys of this type (e.g., the accurate recall of the use of health services and validation of responses). Even with these limitations, the BRFSS remains an important source of health-related data that allows states to evaluate health care coverage and access to health care.

As more states implement health care reform plans, it is essential to continue surveillance

of health insurance coverage and to examine trends of health insurance coverage and use of preventive health services. This study shows the usefulness of the BRFSS in the examination of health care coverage and related health factors among U.S. adults, particularly at the state level. State-based data collected by the BRFSS have already been useful in developing state health plans and may guide policy decisions at the state and regional levels. In addition, BRFSS data may be instrumental in helping health professionals target specific vulnerable subpopulations for specific intervention and educational campaigns.

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Figure 1
Correlation of the Percent of Uninsured Adults Between the BRFSS and the Current Population Survey

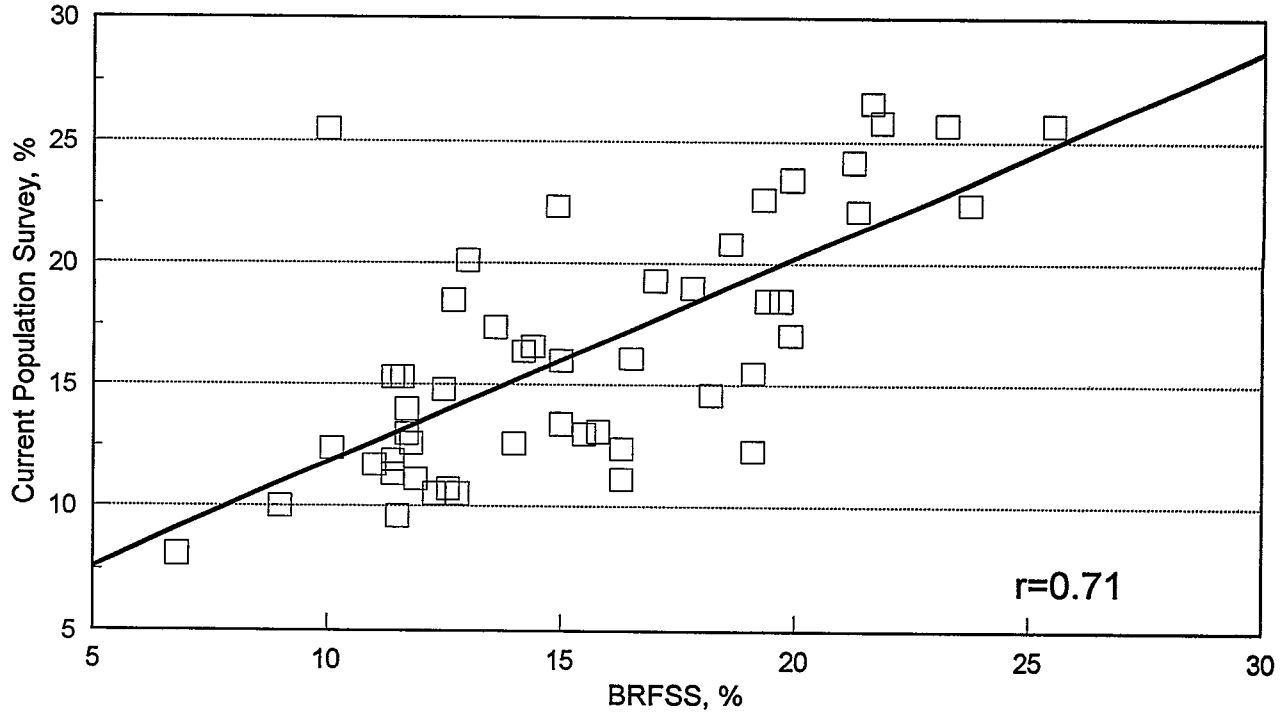


Table 1

Percent of persons ages 18-64 years who were uninsured at the time of interview and who reported that their health status was fair or poor among the insured and uninsured, by state--- BRFSS, 1993

State	Sample Size	Uninsured % (+95%CI)	Fair or Poor Health: Insured % (+95%CI)	Fair or Poor Health: Uninsured % (+95% CI)
Alabama	1694	13.1 (1.7)	9.4 (1.7)	19.7 (6.3)
Alaska	1383	17.0 (3.0)	6.8 (2.2)	7.5 (5.0)
Arizona	1277	19.8 (3.4)	9.2 (2.7)	12.6 (4.9)
Arkansas	1327	19.9 (2.6)	13.0 (2.1)	21.4 (5.4)
California	3071	21.3 (2.0)	8.6 (1.4)	19.4 (4.0)
Colorado	1526	18.3 (2.2)	6.9 (1.5)	14.4 (4.7)
Connecticut	1425	11.5 (2.0)	5.8 (1.5)	7.9 (5.0)
Delaware	1707	15.0 (2.0)	9.4 (1.7)	17.1 (5.2)
Dist. of Cola	1249	10.1 (1.9)	6.3 (1.9)	20.3 (9.1)
Florida	2276	21.3 (2.0)	10.1 (1.6)	14.0 (3.3)
Georgia	1815	14.9 (1.9)	8.0 (1.6)	13.7 (4.2)
Hawaii	1830	6.9 (1.4)	11.1 (2.1)	16.5 (8.7)
Idaho	1444	17.9 (2.6)	8.3 (2.2)	12.3 (5.5)
Illinois	1720	11.6 (1.8)	7.1 (1.4)	20.1 (6.5)
Indiana	1633	14.1 (1.9)	9.0 (1.6)	19.4 (5.6)
Iowa	1359	11.1 (1.9)	4.9 (1.2)	11.1 (5.1)
Kansas	1170	11.8 (2.1)	6.0 (1.5)	14.9 (6.6)
Kentucky	1822	19.9 (2.2)	14.1 (1.9)	22.8 (4.8)
Louisiana	1312	25.6 (2.7)	11.8 (2.2)	16.0 (4.4)
Maine	971	15.8 (2.6)	9.5 (2.2)	16.1 (6.1)
Maryland	3560	11.7 (1.3)	7.5 (1.0)	13.7 (3.7)
Massachusetts	1282	10.1 (1.9)	7.7 (1.7)	8.4 (5.3)
Michigan	1999	11.4 (1.6)	8.7 (1.4)	13.3 (5.0)
Minnesota	2747	9.0 (1.2)	6.7 (1.1)	8.1 (3.7)
Mississippi	1268	19.4 (2.6)	15.5 (2.4)	21.8 (5.8)
Missouri	1167	14.4 (2.3)	10.5 (2.0)	20.7 (6.4)
Montana	939	19.2 (2.8)	8.7 (2.1)	17.6 (6.0)
Nebraska	1365	11.4 (1.9)	6.7 (1.5)	10.9 (5.2)
Nevada	1507	21.7 (2.4)	10.7 (2.1)	9.1 (3.4)
New Hampshire	1234	12.6 (2.1)	6.4 (1.6)	10.8 (5.1)
New Jersey	1227	11.5 (2.1)	5.2 (1.5)	12.9 (6.8)
New Mexico	1059	23.8 (3.1)	8.6 (1.9)	11.3 (4.5)
New York	1922	16.5 (2.0)	8.6 (1.5)	10.6 (3.7)
North Carolina	1864	14.3 (1.8)	11.4 (1.8)	18.1 (5.6)
North Dakota	1378	12.8 (1.9)	8.1 (1.6)	12.6 (5.3)
Ohio	1065	11.7 (2.3)	9.6 (2.0)	12.5 (5.8)
Oklahoma	1148	21.8 (2.7)	10.0 (2.2)	20.8 (5.9)
Oregon	2362	19.2 (1.8)	8.4 (1.3)	11.5 (3.3)
Pennsylvania	1868	12.6 (1.8)	8.1 (1.5)	12.2 (5.1)
Rhode Island	1438	12.0 (2.1)	10.3 (1.9)	15.8 (6.2)
South Carolina	1679	18.7 (2.7)	11.5 (2.2)	20.8 (5.9)
South Dakota	1383	12.8 (2.1)	6.3 (1.5)	14.0 (5.1)
Tennessee	2447	15.1 (1.6)	13.0 (1.6)	18.2 (4.3)
Texas	2078	23.4 (2.4)	9.7 (1.7)	16.2 (3.6)
Utah	1507	15.6 (2.0)	8.9 (1.7)	11.9 (4.5)
Vermont	1550	16.4 (2.2)	7.7 (1.7)	8.0 (3.4)
Virginia	1480	13.7 (2.0)	7.3 (1.5)	11.4 (4.8)
Washington	2182	16.4 (1.8)	6.4 (1.2)	11.0 (3.6)
West Virginia	1819	19.5 (2.1)	17.0 (2.2)	23.3 (5.0)
Wisconsin	1259	12.4 (2.1)	6.4 (1.5)	16.1 (6.2)
Low		6.9	4.9	7.5
High		25.6	17.0	23.3

Table 2

Range in Variations Among States in the Percentage of Uninsured Persons Among Vulnerable Subgroups--- BRFSS, 1993

Subgroup	% Uninsured		Ratio*	
	Low	High	Low	High
Racial/Ethnic Group				
Black¶	**10.6**	**35.3**	**1.3**	**2.4**
Hispanic§	**24.5**	**39.8**	**1.8**	**3.3**
Age (in years)				
18-29	**11.8**	**33.6**	**1.3**	**2.9**
Educational Level				
< 12 years	**14.0**	**55.9**	**1.3**	**3.3**
Family Income per Year				
<=$20,000	**11.9**	**47.6**	**1.8**	**5.0**
Employment Status				
Unemployed	**20.9**	**69.7**	**1.3**	**5.8**

*The percent uninsured in vulnerable subgroup relative to the comparative group.
¶§ Comparisons are made among 18 States with >=10% Black residents and among 7 States with >=10% Hispanic residents.

Table 3

Variation in the Use of Preventive Health Services and Related Health Factors Among Insured and Uninsured Persons--- BRFSS, 1993

	% Insured		% Uninsured		Ratio	
	Low	High	Low	High	Low	High
Blood Cholesterol Check in Past 2 Years						
Total (18-64 yrs)	52.1	67.0	24.3	40.3	0.4	0.7
Men	49.3	66.5	18.7	40.7	0.4	0.8
Women	52.3	67.9	28.7	52.2	0.5	0.8
Digital Rectal Exam in Past 2 Years						
Total (40-64 yrs)	28.7	64.0	10.0	46.9	0.3	0.9
Mammogram and CBE in Past 2 Years						
Total (40-64 yrs)	54.6	75.6	14.0	65.9	0.3	0.9
Pap Smear in Past 3 Years						
Total (18-64 yrs)	81.1	91.9	63.6	84.3	0.8	1.0
Fair or Poor Health						
Total (18-64 yrs)	4.9	17.0	7.5	23.3	0.8	3.2
Men	4.4	17.9	4.5	23.3	0.5	3.6
Women	4.4	18.5	3.3	26.7	0.4	3.8
Couldn't Afford to See a Doctor Because of Cost						
Total (18-64 yrs)	5.2	14.1	28.4	52.5	3.1	7.5
Men	3.4	11.1	19.4	46.4	3.1	8.5
Women	6.4	17.6	27.3	61.0	2.4	8.3
Current Smoking						
Total (18-64 yrs)	12.9	28.7	26.7	47.8	1.4	2.4
Men	13.5	31.5	22.9	48.5	1.2	2.5
Women	12.4	28.7	20.6	50.2	0.9	2.6
Binge Drinking						
Total (18-64 yrs)	4.7	26.4	6.5	37.5	1.1	2.2
Men	7.4	36.5	7.3	48.4	0.6	2.0
Women	2.1	16.5	2.7	26.9	0.7	2.6

BASELINE RESULTS FOR THE ASSESSMENT OF THE IMPACT OF CLINICAL GUIDELINES FOR PEDIATRIC ASTHMA ON MEDICAL CARE UTILIZATION

Jill M. Killian, Mayo Clinic, Mayo Foundation
James M. Naessens, Lynn K. Kelley, Gregory L. Angstman

Asthma is a condition characterized by intermittent partial airway obstruction that can be triggered by a variety of physical, environmental, or emotional factors. It affects approximately 5-15% of children under the age of 15[1]. In children ages 4-12, asthma has been cited as the most common reason for missed school days[2]. In a study done in Rochester, Minnesota, home to the Mayo Clinic, the incidence of asthma in children ages 1 - 14 doubled between 1964 and 1983. The onset of asthma is usually during childhood. The median age of onset of the disease is 3 years in males and 8 years in females[3]. Besides being subject to the serious side effects of their disease, many pediatric asthma patients and their parents have doubts about managing asthma.

A clinical practice guideline for the treatment of pediatric asthma patients was developed in 1994 in conjunction with the Institute for Clinical Systems Integration (ICSI), of which the Mayo Clinic is a participating member, and disseminated to various care sites within the Mayo Clinic for implementation. The guideline closely follows the recommendations of the National Asthma Education Program Expert Panel Report on Diagnosis and Treatment of Asthma[4]. The goals of this guideline are to identify and correctly diagnose asthma in the pediatric age group without significant delay and to provide optimal management of asthma through patient and parent education, avoidance of asthma triggers, comprehensive pharmacologic treatment, and the establishment of a personal patient action plan for exacerbations[5]. A side benefit of better management should be reduced medical care utilization including reduced emergency room visits and hospital admissions. In implementing this guideline, we performed baseline measurements in order to identify areas to focus potential improvement efforts.

The Mayo Clinic's Rochester campus has three primary care sites where a pediatric asthma patient may be routinely followed--Community Pediatrics, Family Medicine, and the Division of Pediatric Allergy. In addition, an acutely ill patient may also be seen in our Urgent Care Center, St. Marys Hospital Emergency Trauma Unit or be admitted to St. Marys Hospital. In addition to being staffed by specialists, the pediatric allergy service employs a full-time nurse educator. The Mayo Clinic also has a patient education center, where the child and his parents may go to attend a class designed to educate the asthma patient. Any site may refer an asthma patient to the patient education center. This is a class intended for a patient with a new diagnosis of asthma.

Methods

All patients under 16 with a diagnosis of asthma with a visit at any of the previously mentioned sites between September and December 1993 were identified. By reviewing the medical charts for these visits, we were able to identify all asthma-related visits for each of the 573 patients during this time period. An asthma-related visit meets one of these two criteria: 1) specific documentation of asthma at the visit, 2) documented symptoms consistent with the Asthma Severity Index, or 3) improvement of the same symptoms with β-agonist treatment. The Asthma Severity Index uses patient estimates of exacerbation frequency, symptoms between exacerbations, exercise impairment, and treatment history; combined with measurements of peak flow rate, spirometry, or respiratory rate; to classify a patient's asthma severity into one of three categories--mild, moderate, or severe. Information for each patient was extracted from the medical record by a registered nurse on the severity of asthma, documentation of patient education and personal action plan, and whether medications were prescribed over the four months. The personal action plan helps the patient's parent determine the child's severity during an asthma flare-up using a combination of peak flow or respiratory rate and symptoms. It gives the parent information regarding medication use based on severity and when to seek medical attention. We also extracted information relating to each visit during the time period. The information included the visit site, whether the visit was documented as an asthma visit by the physician, and whether there was documentation of office-based education, spirometry, pulmonary function testing, and patient height.

Statistical assessments between groups of patients were based on Chi-square tests for nominal variables and Wilcoxon rank sum tests for ordinal and continuous variables, such as age and number of visits.

Results

Overall, the 573 patients made a total of 1,119 asthma-related visits during the four-month study period. Five patients had 10 or more visits with a maximum of 15 visits. In addition, there were 116 documented phone calls relating to an asthma visit. For the most part, these were calls to a primary care physician for a prescription refill. Seventy-seven patients were hospitalized a total of 85 episodes representing almost 8 percent of all visits. An additional 381 visits (34 percent) were acute care visits to either the emergency room or Urgent Care Center.

In order to compare the utilization patterns across primary care sites, and since in our practice patients are not assigned to a primary care practitioner, we categorized the patients by the first primary care site they visited during the timeframe. With this classification, 42 percent of the patients were managed by the pediatric allergy specialists, 24 percent were followed by the generalists in Community Pediatrics, 8 percent were followed by Family Medicine, and 25 percent received all of their asthma care during the four months in acute care settings (Table 1). However, these patients may have received primary care outside of the Mayo system, which we did not collect. A small group of patients was seen at multiple primary care sites. These were primarily patients who were referred to Pediatric Allergy from a generalist.

Patient gender was not significantly different based on first primary care site. However, age did vary significantly between groups of patients ($p = 0.0009$) . Only one of the 16 patients less than age one was seen in Pediatric Allergy, while infants aged less than one year made up 4 - 5 percent of each of the other three groups. Community Pediatrics had a significantly higher proportion of 1 - 4 year olds (42 percent vs. 22 - 29 percent for the other groups).

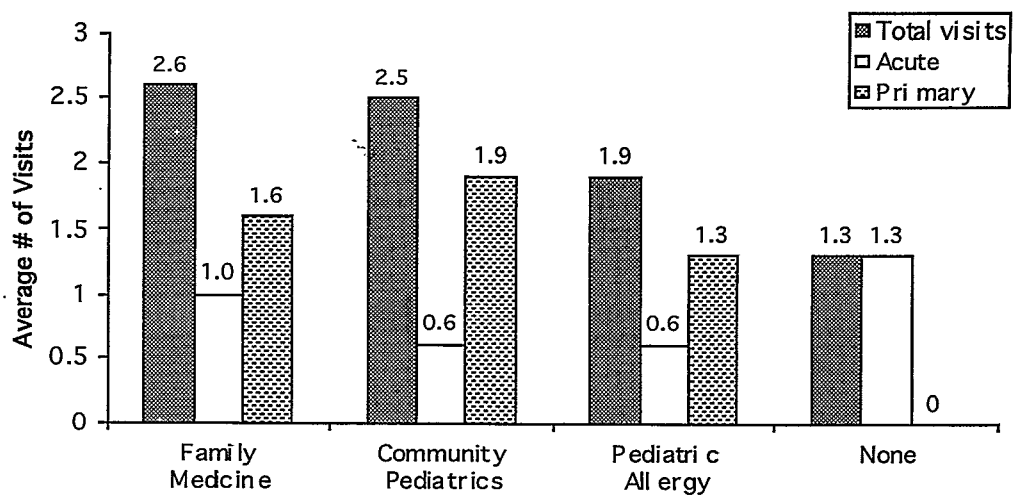
Unfortunately, the severity of asthma was not documented sufficiently to compare the type of asthma patient being seen at each site. In an attempt to assess the severity, we looked at medication use and hospitalizations for each of the patient groups. The percent of patients on medication ranged from 96 to 98 percent across the four sites and the percent of patients hospitalized in the four months ranged from 13.3 to 13.5 percent.

The rate of visits per patient during the timeframe was significantly different across the four groups. Both Family Medicine and Community Pediatrics patients averaged 2.5 total visits, Pediatric Allergy patients averaged 1.9 visits, while those without primary care contacts averaged 1.3 total visits. Meanwhile, all the visits by those without primary care were acute visits, while Community Pediatrics and Pediatric Allergy patients averaged 0.6 acute visits (Graph 1). Furthermore, over two-thirds of the acute visits made by patients attributed to Pediatric Allergy were made prior to the Pediatric Allergy visit. Over 60 percent of the acute visits by Family Medicine patients and 50 percent by Community Pediatric patients were made after the primary care visit. When directly comparing Pediatric Allergy patients to those assigned to either Family Medicine

Table 1: Patients Categorized by First Primary Care Site

Site	N	%	% Male	Age (years) Mean ± s.d.
Pediatric Allergy	244	43	59.0	7.6±4.0
Community Pediatrics	141	24	57.4	5.8±4.2
Family Medicine	45	8	64.4	6.9±4.0
None	143	25	66.4	7.1±4.6

Graph 1: Utilization by First Primary Care Site



or Community Pediatrics, the Pediatric Allergy patients had significantly fewer total visits (1.91 vs. 2.55, p<0.001), but not significantly fewer acute visits (0.63 vs. 0.72, p=0.520).

Utilization of acute care services were also compared. Patients without primary care and those in Family Medicine had similar numbers of visits to Urgent Care and the emergency room, while those followed by Pediatric Allergy and Community Pediatrics had more emergency room visits than urgent care visits (Graph 2). Mean Urgent Care visits and emergency room visits per patient were significantly lower in the two Pediatric groups.

To investigate whether the lower utilization among Pediatric Allergy patients is due to better management of the patient's asthma care, we examined the documentation of care provided to the patients. As noted earlier, the goals of the pediatric asthma guideline include increased patient and parent education, the establishment of a personal action plan, and comprehensive pharmacologic treatment. Each of these goals is driven by the patient's asthma severity. Although there was much room for improvement, 16.4 percent of the patients followed by Pediatric Allergy had their severity documented. This is a significantly higher level of documentation of severity compared with 6.7 percent in Family Medicine, 4.3 percent in Community Pediatrics, and 0.7 percent in those without primary care. In addition, the Pediatric Allergy patients were the only ones with any referrals to the patient education center and with personal care plans documented. When visit-level documentation was reviewed, visits with Pediatric Allergy had significantly higher rates of office-based education ($p < 0.0001$); documentation of the visit as an asthma visit by the physician in the patient's medical record ($p < 0.0001$), and respiratory testing ($p < 0.0001$). (Table 2) As these are important components of a management plan,

Graph 2: Utilization of Acute Care Services

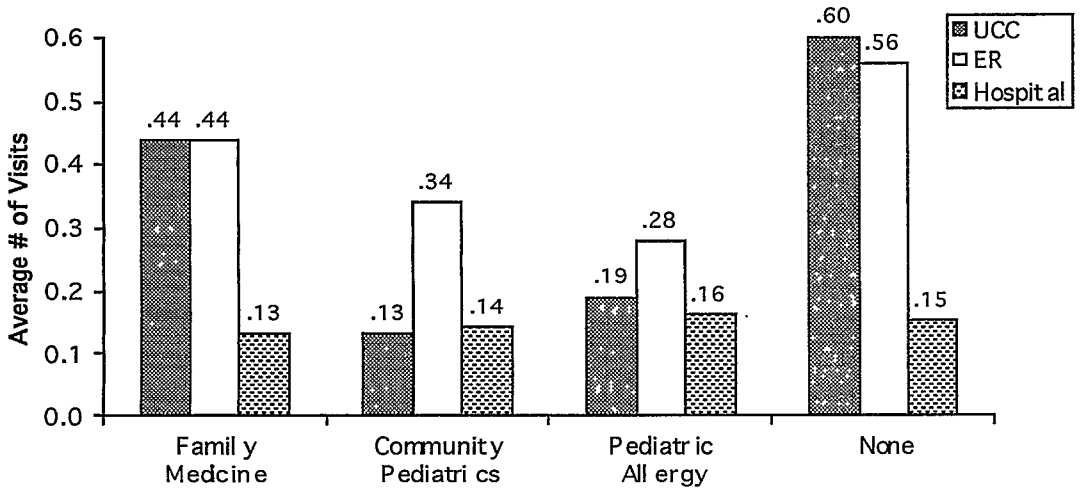


Table 2: Visit-Level Documentation Across Sites

	% of visits with office-based education	% of visits documented as asthma	% of visits with respiratory testing documented*
Family Medicine	0	72.6	4.8
Community Pediatrics	1.2	68.1	9.0
Pediatric Allergy	10.8	96.0	29.6
Urgent Care Center	0	50.6	5.4
Emergency Room	0	71.0	20.2
Hospital	0	76.2	16.5

*respiratory testing includes either pulmonary function test or spirometry

more frequent documentation probably coincides with a higher level of attention and better management.

Discussion

Our study has several limitations. In the course of treatment of a pediatric asthma patient, a four-month window of visits is a relatively short timeframe for analysis. The seasonal aspects of the disease were certainly not captured. In particular, some of the patients without primary core visits may have had a regular source of care outside of our study period or outside of the Mayo system.

Our comparison of utilization by provider group was based on the assignment of all utilization to the first primary care site in which the patient was seen. It is not based on the patient's identified regular source of care. When examining utilization rates, we do believe that this may be a reasonable classification of patients in that the Pediatric Allergy patients had a majority of acute care visits prior to their first primary care visit. This suggests that many of these patients may not have previously had a regular primary care provider, or they may have been newly diagnosed asthma patients. Once asthma care is managed by Pediatric Allergy, it appears that total utilization is reduced.

Finally, due to the lack of severity documentation, we were unable to adjust for differences which we suspect exist between the patients being treated by the different provider groups. Severity is expected to be highly correlated with the rate of visits, particularly for acute exacerbations. In addition, the guideline calls for different actions based on the level of severity. Patients with mild asthma do not require the level of education and management that is necessary for patients with moderate to severe asthma. The other related factor that would have an impact on utilization that we did not collect is the duration of disease since diagnosis. Newly diagnosed asthmatics are expected to have more frequent visits until the disease is adequately managed.

These measures support the implementation of the pediatric asthma clinical practice guideline. Each site analyzes its own data and compares their pediatric asthma patient management process to that of the guideline. The guideline suggests goals for managing the disease. Each site's implementation team uses these measurements to focus their improvement efforts.

In the early stages of implementation, one of the primary care sites put its emphasis on two points: 1) Patients with moderate or severe asthma should be referred to patient/parent education programs, and 2) Patients with urgent care or emergency room visits for asthma should have a follow-up visit with their regular source of care within eight days of acute care. Preliminary data suggests that these areas both have continuing potential for improvement and would benefit the patient.

In summary, we have seen that pediatric asthma patients make a large number of contacts with the medical care system for both primary and acute care services. The rate of visits appears to be different for patients who are seen by different providers. The provider group that most closely follows the guideline, Pediatric Allergy, also has the lowest utilization of allergy-related visits. We have also seen in the guideline implementation process that groups of providers are more actively engaged in the quality improvement process and are able to focus their efforts when they have data available that relates directly to their own performance.

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Third Through Fifth Plenary Session

National Committee on Vital and Health Statistics

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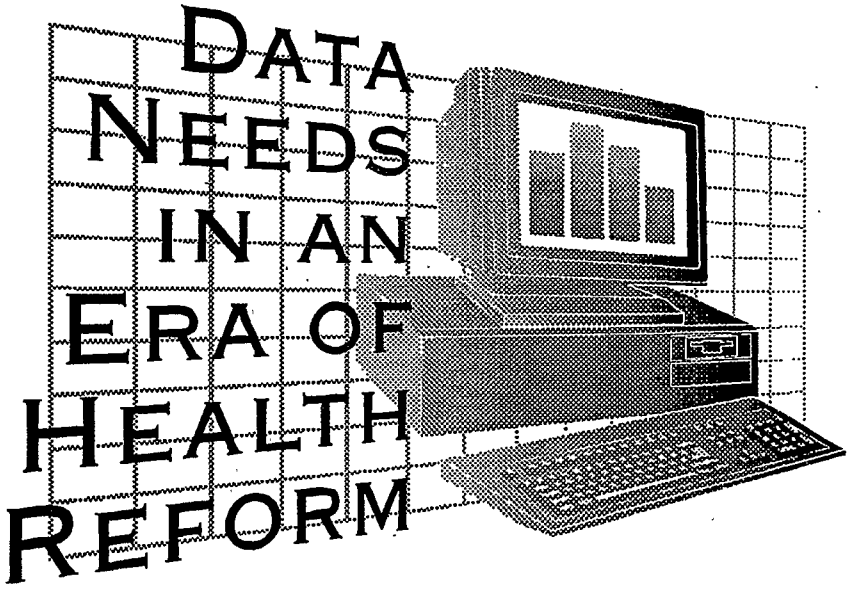


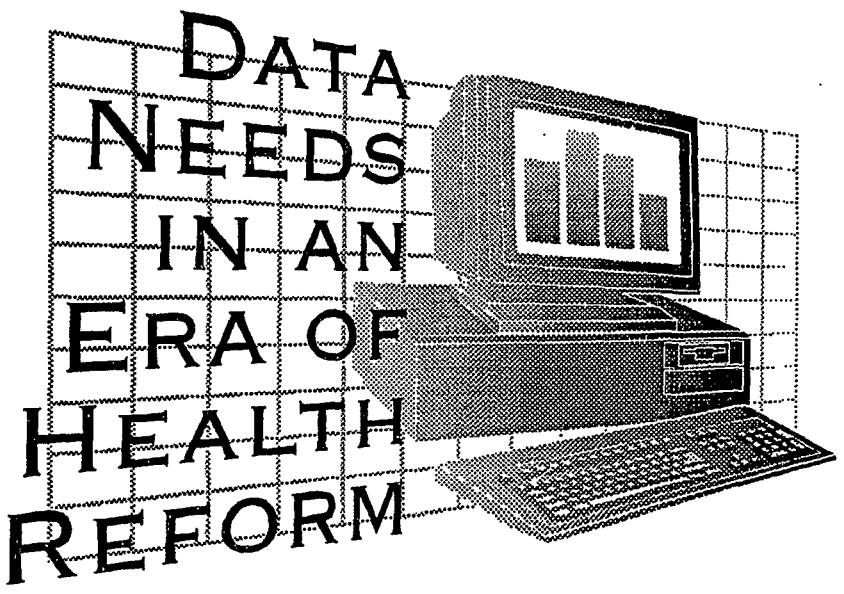
NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS'
45TH ANNIVERSARY SYMPOSIUM

Third through Fifth Plenary Sessions

This portion of the program, together with the Sixth through Eighth Plenary Sessions, will be printed under separate cover. All conference participants will receive a copy.

Session U

Building an Improved Information Infrastructure



BUILDING A CORE DATA SET AND INFORMATION INFRASTRUCTURE IN A PUBLIC HEALTH AGENCY

Michael G. Medvesky
New York State Department of Health
Patricia A. MacCubbin, Lloyd F. Novick

The New York State Department of Health (NYSDOH) has been moving toward the goal of making public health information more accessible and useable for public health providers. This undertaking involves providing electronic access to health information to counties, local providers, community-based organizations and consumers through the development and support of an information communication infrastructure.

Background

In the past, the NYSDOH has seen a wide variation in access to, and use of, health information across local health departments and other public health practitioners in New York State. Smaller county health departments without planning/evaluation staff were at a disadvantage in collecting and presenting health information needed for health surveillance, program needs assessment, and monitoring and evaluation activities. Even the larger county health departments, with planning/evaluation staff available for these tasks, often utilized information that was out-of-date, with more current data being available.

County health departments receive reimbursement from the NYSDOH for public health activities. As part of this reimbursement process, each county health department is required to prepare a biennial "community health assessment" that presents the demographics of the county's population, details progress on various health status indicators, and identifies service needs and gaps in services. In the past NYSDOH generated and circulated hardcopies of the data necessary to complete the assessment. Local health departments utilized and interpreted this information. This cumbersome process left much to be desired. A Robert Wood Johnson Information for State Health Policy grant provided funding for the state to research and develop applications for the Internet. This provided the opportunity to make relevant health information available electronically to the public health community.

More recent efforts in developing a health information infrastructure can be classified into two components:

- Making health information more useable and accessible to the public health and health care providers and to consumers;
- Developing and supporting an information communications infrastructure.

Health Information More Useable and Accessible

NYSDOH Information System Inventory

In an effort to make health information more useable, NYSDOH needed to know exactly what data were being collected throughout the department. The NYSDOH conducted an inventory of existing information systems. The resulting information was assembled in the NYSDOH Information System Inventory. Topics covered in the inventory include:

- Information system/data set name
- System/data set owner
- Contents of system/data set
- Demographic information available
- Geographic information available
- Data items available for possible record linkage activities
- Level of data
- Timeliness
- Data collection method
- Data utility/data limitations
- Restrictions for the use of the data
- Any public reports utilizing this information system/data set
- Contact person for questions about this information/data set

The inventory will be available electronically on the NYSDOH Gopher server.

NYSDOH Public Gopher Server (Internet Access)

The Robert Wood Johnson Information for State Health Policy grant supported the Department's efforts to make health information accessible via the Internet through a NYSDOH Gopher server. The NYSDOH public Gopher server is menu driven and part of the Department's public access network. Health data are available in prepared files on the Gopher. The NYSDOH Gopher provides public access to any NYSDOH information that can be requested through the Freedom of Information Law. Data queries are not possible through this server. Files are available in a variety of formats:

- Text
- Spreadsheet
- Graphic

In addition to consumer health information (hotline numbers, disease fact sheets, health service sites) and official NYSDOH reports and publications, a core data set is available electronically on the NYSDOH Gopher server. This data set includes Healthy People 2000 22.1 Core Indicators, other Healthy People 2000 indicators, program-identified process and outcome measures, county-specific trend information for specific health indicators, county summary tables of multiple health indicators, and small area (zip code) information on selected health indicators.

Health Information Server(s) (Data warehouse)

While publicly accessible health information will be made available via the NYSDOH Gopher server on Internet, a Health Information Server (HIS) is being developed to serve as a common electronic repository of "sensitive" health information. Automated databases on the HIS will be populated by appropriate "extracts" from multiple central data sets constructed with information supplied by local health departments, other local providers, or from state or federal data collection activities. The HIS will be available via the Health Information Network (HIN), thus allowing the Department the ability to limit access and provide the necessary security.

Primary and Preventive Care Geographic Information System Application

The first major HIS application will be the Primary and Preventive Care Geographic Information System (PPCGIS). The PPCGIS software is being developed as a data query/analytic tool; the HIS "health data warehouse" will be the source of the health information for the PPCGIS. The major design features of this application include:

- Prepackaged, affordable software that will operate on a user's PC
- User-friendly interface and operation, including on-line help
- Ability to handle different geographical subdivisions, e.g., county, zip code
- Data selection and extraction capability, including selection of combination of areas
- Ability to generate tables based on variable and area selection
- Ability to generate graphs based on data selection
- Ability to handle data input on site
- Mapping capability
- Regular program and data updates
- Evaluation and revision of the system

As mentioned, the Primary and Preventive Care Geographic Information System will be accessible via the HIN, which is a CDC Information Network for Public Health Officials (INPHO) Project. Other highlights of the PPCGIS include:

- Client-Server application, where the server hardware and software are components of the HIN.
- Server will provide access to a very large database containing a wide range of preprocessed health and sociodemographic data organized at multiple levels of geography.
- Data will be accessible to counties, providers, advocates, NYSDOH staff, and others involved in health planning.
- Access to the server will be accomplished through dial-in lines and direct connection.

Development and Support of an Information Communications Infrastruture

The Public Health Information System is comprised of three parts, HEALTHCOM, NYSDOH Gopher and Health Information Network.

HEALTHCOM/E-Mail

HEALTHCOM is an internal NYSDOH wide area network. HEALTHCOM functions as the internal communications system for the NYSDOH Albany-based staff, Regional Offices and Statewide District Offices. It includes file transfer, login, printing, access to health care data, research resources (such as the Internet), office automation functions, e-mail exchange with every health care facility in New York State, and client/server support for nearly 2,400 internal Department computer hosts. The HEALTHCOM network supplies appropriate health-related statistics and other information products to the public sector via the Department's Internet Gopher.

The external e-mail services on HEALTHCOM support 4,000 dial-up connects to hospitals, nursing homes, diagnostic and treatment centers, and clinical laboratories throughout the state. This e-mail network provides a bidirectional data highway for a variety of electronic batch-type applications used for automated data collection and distribution between the Department and these facilities. Data collection includes health care finance, vital records, disease and heavy metals registries, health systems management and regulations, and clinical laboratory evaluation. For example, 77% of all State birth certificates and 96% of all State child blood lead test reports are collected via e-mail.

Another feature of the e-mail network is that it is designed to be contiguous between internal and external networks, so that any user on a peer host computer in the NYSDOH internal network can directly exchange mail with, or send fax documents to, the health care facilities on the dial-up mail connects or Internet/Bitnet international networks. For example, the Bureau of Communicable Disease Control sends Problem Alerts through e-mail and bulk fax.

NYSDOH has also implemented an external access network, StateLine, as a "meeting place" for peer connections to other state agencies and for gateway services to the entire New York State mainframe network, including the State Education network, connecting elementary and secondary schools and libraries throughout the state. StateLine includes an internal connection and Gopher servers.

Public Access Network

The Public Access Network consists of the NYSDOH Gopher server, described previously, and access to the Internet and the World-Wide Web, as seen in the figure. This figure illustrates the one-way access feature of the design.

Health Information Network (HIN)

The Centers for Disease Control and Prevention has awarded NYSDOH a three year Information Network for Public Health Officials (INPHO) grant to extend the existing NYSDOH network infrastructure to county health departments. The HIN, a subnetwork of HEALTHCOM, will establish a standardized, real-time, data communications network, linking the county and state health departments. Participants on the HIN will have access to the NYSDOH public access network and to Internet (outbound only), including access to CDC. This will ultimately include services such as Gopher, telnet, file transfer, and mosaic.

The HIN will include centralized Health Information Servers to support data submission and distribution for the counties on the subnetwork. Ultimately, the server will support a relational data base and the data entry/query functions needed to integrate existing internal health record databases with input from immunization records and other key public health programs. When fully operational, the server will allow participants to access and submit health data on the subnetwork using various methodologies such as client/server applications, Gopher, direct login, file transfer and e-mail.

The HIN will provide greatly increased information exchange with the county health departments and health providers in NYS, and provide Internet access for county health departments, giving them access to NYSDOH public information products on the NYSDOH Gopher and Internet-based applications at the CDC. The HIN will also support a centralized immunization registry linked to other key NYSDOH health data systems on the Health Information Server . The server will deliver appropriate levels of data exchange and access to its data bases for local health units, private providers, and State and Federal agencies. Larger counties will access the HIN through dedicated connections. Smaller counties will have HIN access through a 1-800-number dial-up number. By the end of the first year of this three-year grant, we expect to have 20 counties on the HIN.

Future

The NYSDOH is committed to continued support and expansion of the NYSDOH Gopher and PPCGIS. Local information networks, such as those developed by diagnostic and treatment centers, hospitals, providers, etc., will be utilizing the Health Information Network. Existing information systems will move to the HIN for data transfer and analysis. The HIN environment will be used for health education and training purposes.

Acknowledgements:

The authors would like to acknowledge the contributions of Dr. Ivan Gotham, Frank Kuwik, Colene Byrne, Anne Conrad, and Cynthia Gorzynski.

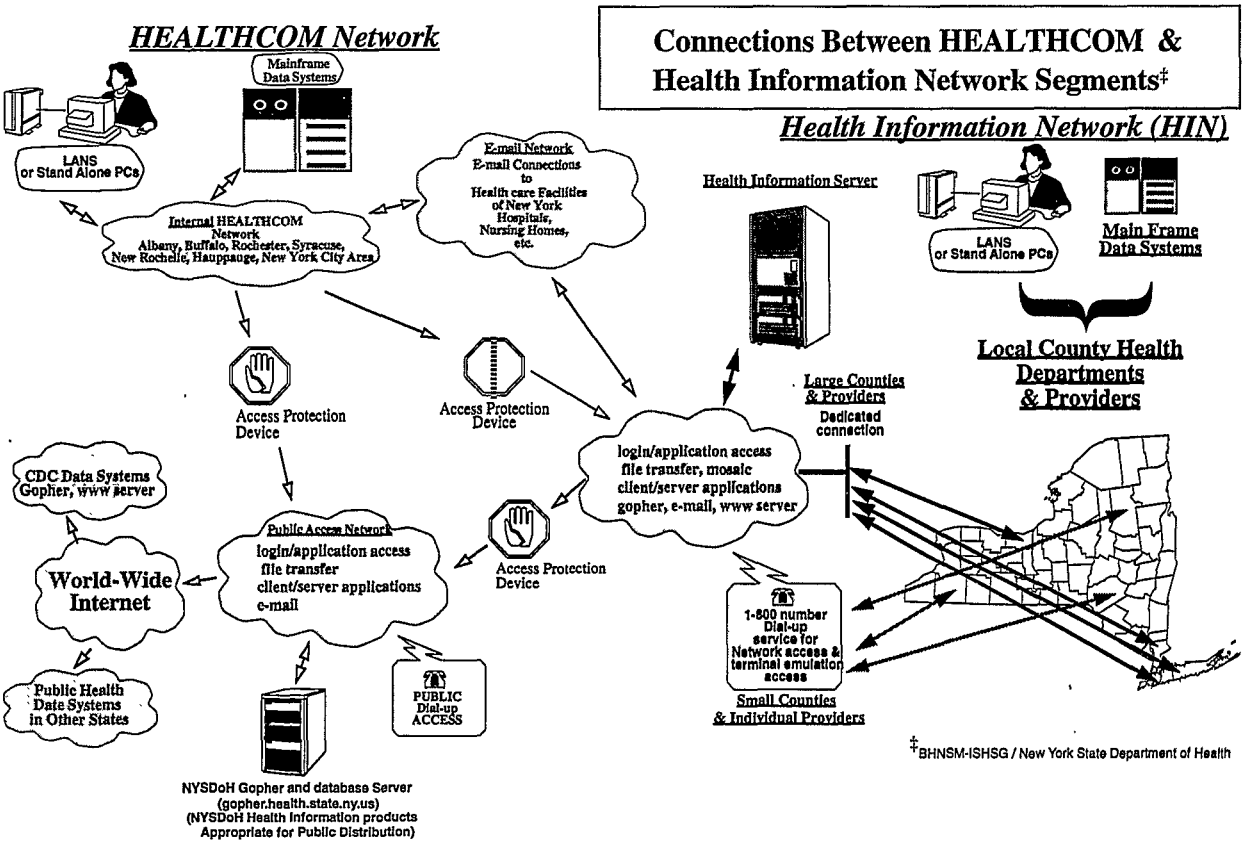
New York State Department of Health
Contact Phone Numbers and E-mail Addresses

OVERVIEW:
Michael Medvesky, Director
Office of Public Health
Information Group
518:474-2543
mgm06@health.state.ny.us

HEALTH INFORMATION NETWORK:
Dr. Ivan Gotham, Director
Bureau of HEALTHCOM Network
Systems Management
518:473-1809
ijg01@health.state.ny.us

PRIMARY & PREVENTIVE CARE GEOGRAPHIC INFORMATION SYSTEM:
Colene Byrne, Coordinator
Information for State Health
Policy Project
518:473-4708
cmb04@health.state.ny.us

NYSDOH Gopher: gopher.state.health.ny.us


HEALTHCOM Network
Connections Between HEALTHCOM & Health Information Network Segments‡
Health Information Network (HIN)
Mainframe Data Systems
LANS or Stand Alone PCs
E-mail Network
E-mail Connections to Health care Facilities of New York Hospitals, Nursing Homes, etc.
Internal HEALTHCOM Network
Albany, Buffalo, Rochester, Syracuse, New Rochelle, Hauppauge, New York City Area
Health Information Server
LANS or Stand Alone PCs
Main Frame Data Systems
Local County Health Departments & Providers
Access Protection Device
Access Protection Device
Large Counties & Providers
Dedicated connection
login/application access file transfer, mosaic client/server applications gopher, e-mail, www server
CDC Data Systems Gopher, www server
Public Access Network
login/application access file transfer client/server applications e-mail
Access Protection Device
World-Wide Internet
1-800 number Dial-up service for Network access & terminal emulation access
Small Counties & Individual Providers
Public Health Date Systems in Other States
PUBLIC Dial-up ACCESS
NYSDoH Gopher and database Server (gopher.health.state.ny.us) (NYSDoH Health Information products Appropriate for Public Distribution)
‡BHNSM-ISHSG / New York State Department of Health

LESSONS FOR NATIONAL STANDARDS ON HEALTH DATA: STATE PRACTICES IN BUILDING DATABASES ON HOSPITAL INPATIENT STAYS

Anne Elixhauser, Agency for Health Care Policy and Research
Roxanne Andrews, Judy Ball, Rosanna Coffey, Meg Johantgen, Pat Purcell

States with data systems are requesting leadership on standards and information system design to improve data systems, collect comparable information, and eventually connect states to a national information system. States without data systems are asking for guidance on developing them. The opportunity exists to help states adopt standards that move the nation closer to a uniform health care information system. To understand the effects of health policy, policy-makers and researchers need data that is comparable across states.

This project attempts to enlighten the development of data standards by exploring their use in hospital inpatient data. We compared states' data elements with standards that have been promulgated: UHDDS, proposed by NCVHS and accepted by US DHHS for hospital discharge data; UB-92, required by HCFA for Medicare reimbursement; and OMB Directive 15, a standard for collecting information on race/ethnicity.

The sources of information for this study were 1993 data layouts and other documentation from 12 states/hospital associations with hospital inpatient databases. This study found considerable diversity in the variables collected and in their coding. For example, all states collected total charges and eight included detailed charges but at different levels of aggregation, reducing comparability across states.

The greatest variation was found in the coding of variables. Coding for expected pay source was especially diverse: in 5 of the 12 states it was impossible to isolate Blue Cross/Blue Shield as a payor.

Variations in Coding of Payor Source

Pay Source	Number of States
Medicare	12
Medicaid	12
Other government	1
Workers' compensation	9
Blue Cross/Blue Shield	7
Commercial insurance	11
HMO	6
Self-pay	11
Other/unknown	9

This study found that despite the existence of standards, none of the 12 states strictly follows a standard. Therefore, a compelling incentive is necessary for uniform standards to be adopted across the nation. Otherwise a broad and continual education program will be required and may still be ineffective in achieving conformity to national standards. At a minimum, federal guidance and support will be necessary to encourage the acceptance of standards.

THE BALTIMORE CITY/MARYLAND STATE SEXUALLY TRANSMITTED DISEASE REGISTRY: IMPROVING DISEASE SURVEILLANCE THROUGH COMPUTERIZED REPORTING

Beth Erickson, Light Industries
Wayne Brathwaite

This presentation describes a collaborative effort between the Baltimore City Health Department (BCHD), the Maryland State Health Department, and Light Industries, a computer consulting firm based in Millersville, Maryland, to develop a shared, computerized Sexually Transmitted Disease Registry. Wayne Brathwaite, the co-author of this presentation, is the Manager of the STD Program in Baltimore City.

We present the Registry as a model of a public/private collaboration. We feel that the way we've worked together is different from the typical client/vendor relationship where a client contracts out to a vendor for a specific, defined task, and when that task is finished, so is the relationship and the commitment to see it succeed. Rather, what has developed between us over the course of this and previous projects is a deep level of commitment to some long-term computerization goals. There is a mutual respect for the talent and expertise among us that has created a synergistic effect. The result of this synergy has been a series of projects which we think are more successful and effective than would have resulted out of a typical client/vendor relationship.

The objectives of this presentation are to: (1) Provide background on why the Registry is needed, the benefits of the registry, and how the project collaborations came about, (2) Describe the methods used to design and implement the Registry, (3) Describe the results of the design process, and (4) Provide some observations and recommendations.

BACKGROUND

Why an STD Registry is needed

While the computerized STD Registry collects information on syphilis, gonorrhea and chlamydia, the impetus for the original, manual Registry was the need for information about syphilis. Syphilis is the type of disease where a positive test does not necessarily represent current infection. Therefore, information about previous test results and treatments is necessary to determine how to respond to the current positive test.

In addition, previous test and treatment status plays a role in determining whether to initiate disease investigation. This is the process during which Disease Intervention Staff (DIS) go into the field to: 1) Verify treatment, 2) Coordinate treatment for those who haven't received it, and 3) Conduct contact investigations with partners of the case.

There are about 20,000 to 30,000 reports of positive syphilis in Baltimore City each year. After a review of the Registry's historical records, only about 20-30% of these reports are determined to need field investigation. In this way, the Registry aids in making the most effective use of limited personnel resources.

The manual Registry was developed in 1960 and until 1993, when the computerized Registry was implemented, the Baltimore STD program maintained reports of positive syphilis on 5" by 8" index cards which were stored in an electric cardveyor.

Benefits of Computerizing the Registry

The following benefits have been achieved with computerization of the Registry:

1. Simultaneous, multi-user access. With the manual system, only one staff member could use the cardveyor at a time.

2. Faster retrieval of information. Using the manual system, it took time to locate the correct cardveyor shelf, and within it, the right card. With the new system, a record is located with several keystrokes.

3. Permanent record location. With the manual system, once a card was misfiled, it (and the information on it) was lost indefinitely. Computerized records can't be misfiled.

4. Increased accuracy. With the manual system there was no routine in place to detect data recording errors. The computerized system provides for automatic validation of data as it's entered.

5. Increased legibility. Illegible handwriting and fading ink made some of the morbidity cards difficult to read. This problem is eliminated with electronic display.

6. Standard data format. With the manual system, data could be entered on the index cards in a haphazard format. Now, all users enter data using the same screens, which standardizes the order and format in which data are recorded.

7. Redundant data storage. There was no way to create a back-up of the card system. In the event of a fire, for instance, the Registry would have ceased to exist. Now, the Registry is archived daily and in the event of a system failure or other data loss, the Registry datafiles can be restored, and the system would be up and running in a few hours.

8. Ease of merging records. In the manual system, subsequent reports of infection were either listed on the previous card, or a new card was stapled to the existing card. With the computerized Registry, subsequent disease reports are automatically linked to the previous records of the case, resulting in a cumulative electronic record of disease status over time.

9. Decreased data entry time. In the new system, demographic data doesn't need to be entered with each new report. Previous data can be edited for the new record, and the old data remains accessible to the user.

10. Increased capability for data analysis. Given the scope of the data collected and the volume of records entered into the system each year, the possibilities for data analysis are unlimited, for instance, to produce statistical reports, to evaluate programs such as STD surveillance and partner notification, to answer research questions and to write publications. The data also provide a compelling addition to grant applications.

Benefits of a City/State collaboration

There were several reasons why the City sought collaboration with the State STD Program which is directed by Kim Seechuck:

1. Like the City, the State also maintained a manual STD Registry. Computerization of their disease reports would provide the benefits just discussed.

2. The City and State had already established a collaborative relationship whereby they shared information about tests reported in each other's jurisdictions.

3. The establishment of a City/State STD Registry is consistent with *Healthy People 2000* objectives related to the development of surveillance and data systems across State and local agencies.

Both the City and the State obtained funding for the Registry from the Centers for Disease Control and Prevention. System design responsibility was divided based on the amount of money each party could contribute to the project. Since Baltimore City had more funds, they were responsible for the design and implementation of the core system modules. The State is responsible for the design of two Disease Investigation modules.

METHODS

The process by which the concept of the Registry was developed into the system that's in use today was accomplished through the following steps:

The first step was to identify the technical resource. Since 1988, the BCHD Sexually Transmitted Disease Program had worked successfully with Light Industries on several projects, among them a clinical and laboratory information system for the City's two STD clinics. During those collaborations, Light Industries staff had acquired considerable knowledge about the field of public health and STDs in particular, and were well acquainted with how the STD program functioned.

Next, specifications were developed by Light Industries. This process began when the STD Program staff provided Light Industries with an outline of how the Registry should work. The systems engineers and programmers at Light Industries reviewed the material, asked questions, were provided clarification by the Health Department staff, and at the end of this process, which was repeated over the period of a few months and over the course of several meetings,

Light Industries synthesized all the information and developed software specifications. The specifications outlined in detail what the system would do and how it would look to the user.

Upon review and acceptance of the specifications by the BCHD STD Program Manager, the software code was written by Light Industries.

Next, the software was installed, and there followed a period during which coding modifications and problems resulting from conceptual design were identified and resolved.

Finally, the revised code was installed and at that point, migration from the old manual system, to the new computerized system began.

Since then, the Registry has been undergoing a continual process of enhancement. Users identify new ways that the system can help them do a certain task, and a new module is added to the basic software platform that was installed several years ago. Nonetheless, the development steps outlined here are followed, no matter what the scope of the module being developed.

RESULTS

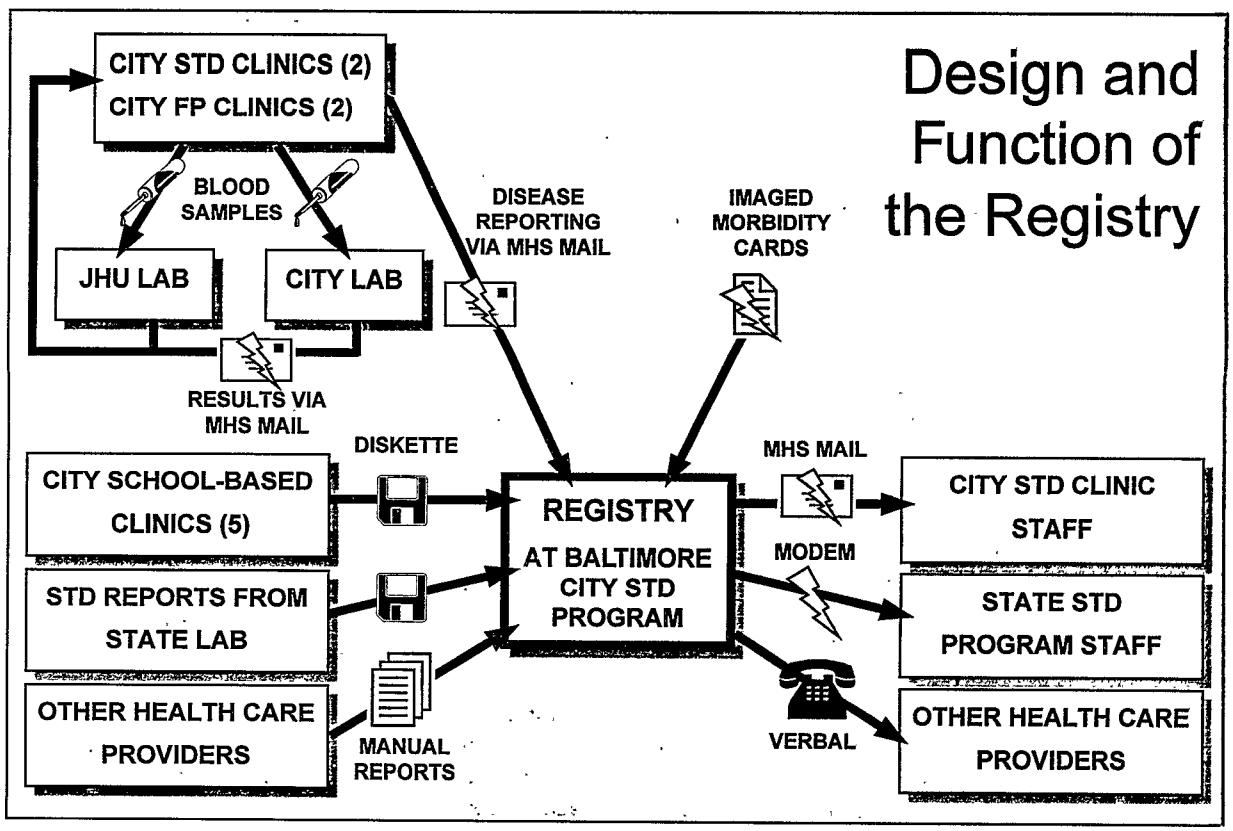
The diagram below provides an overview of the design and function of the Registry. It is maintained on a local area network at the administrative office of the Baltimore City STD Program. The Maryland State STD Program has access via a remote telecommunications link. Reports of STDs generated at the State Lab are transmitted to the Registry via diskette.

Much of the STD testing at the City's two STD clinics and two Family Planning Clinics are done at two off-site labs (the City Lab and a research lab at Johns Hopkins University). Requests for STD testing from these clinics are submitted to the labs via a Message Handling System (MHS) data transfer protocol. Test results are transmitted back to the clinics via the MHS. Upon receipt of test results, the clinics, in turn, transmit the disease report, along with the associated patient demographic data, to the Registry via an MHS protocol.

Five City School-Based Clinics can submit results to the Registry via diskette. Written reports from other test sites are manually entered into the Registry upon receipt at the City or State STD Program offices.

An optical disk stores images of the STD morbidity reports from the cardveyor. These images are linked to subsequent electronic disease reports.

The Registry provides the following capabilities:



1. It provides for quick access to case and contact records using one of several search methods.

2. It captures demographic information of persons tested for syphilis, gonorrhea or chlamydia and allows for free text data entry via an automated notepad function.

3. It collects information about test results.

4. It collects information about the type of treatment prescribed. A pull-down menu allows the user to select from a list of valid treatment choices. Treatments can be marked as adequate or inadequate by STD program staff, allowing for analysis of adherence to standard treatment protocols by provider-type.

5. Information about the Disease Investigation process is collected, for instance, whether a field investigation was initiated and if the case was located and interviewed. Information about stage of disease and case disposition is also collected.

6. Information about contacts of the index case can be entered into the system, for instance basic demographic and locating information, exposure information and results of the Contact investigation. The information collected in this module is very powerful. Due to the fact that patient records are linked to contact records, who may become cases themselves if they test positive, with contacts of their own, this module provides valuable information for the identification and analysis of disease clusters.

7. Historical morbidity cards from the cardveyor are scanned into the system using an optical scanner. The images are linked to an identifying electronic record which contains just a few demographic fields. If a subsequent test is reported for an individual with an archived image in the system, the new electronic report is linked to the image. A notation appears on the demographic screen of the new record that an image exists for that person. The image can be displayed on the screen by pressing a hot key.

8. The system imports electronic records from labs which conduct STD testing. Using a predefined set of matching criteria, the system displays potential matches between the imported (new) disease reports and existing data. The user has the option of viewing the match criteria for each record before selecting the best match set.

9. The Registry contains some standard system reports (disease status by race, sex and age, for instance). In addition, authorized users have access to an off-the-shelf report writing software program, and can generate ad hoc reports via access to the Registry databases.

CONCLUSION

The STD Registry provides a model of how public and private sectors can collaborate to respond to national health objectives.

First, through automated reporting and multi-user access to morbidity information, the Registry addresses national objectives to increase the proportion of providers who correctly manage cases of STDs. Currently, work is underway to expand on-line access to the Registry. By the Fall of 1995, clinicians at the City's two STD clinics will be able to access the Registry databases electronically from the computer workstations in the exam rooms. In addition, we've applied for funding to develop a method by which authorized private providers in the community could access the Registry from their practices.

Secondly, the city/state collaboration provides a model system for the transfer of health information across geopolitical boundaries - one of the *Healthy People 2000* surveillance and data systems objectives.

Lastly, because the Registry databases provide a vast wealth of information for analysis and research, the Registry responds to *Healthy People 2000* objectives for the periodic analysis and publication of data to measure progress toward national health objectives.

Obstacles

An obstacle encountered in the city/state collaborative relationship was the result of dissimilar administrative goals. Both programs have similar reporting responsibilities, but the City STD Program has an additional responsibility to provide clinical services and disease field investigation. Since the City was responsible for the design of the Registry's STD re-

port module, data elements were included which would facilitate their clinical management and field investigation responsibilities.

After using the system for some time, the State STD Program decided that a condensed version of the STD report module would better suit their administrative needs. They worked with Light Industries to modify this section by deleting the clinical and disease investigation data elements. This solution solved the problem, however because there are now two versions of the software in operation simultaneously, the complexity of system maintenance and modification has increased.

The second and most difficult obstacle we've encountered has to do with fiscal issues. With a project of this nature one might expect that there would be problems getting people to work together or problems with hardware and software design or implementation. But that wasn't the case.

The first fiscal obstacle had to do with obtaining funds. This project began in 1992 and is still in progress. After all is said and done, this will probably be a five year project, but what we've had to do is develop it one year at a time, within the confines of fiscal funding cycles. Our belief is that if we'd been able to obtain a longer funding commitment, thereby providing a broader horizon for project planning, the result may have been a more efficient use of resources, and an even more successful project.

The second obstacle has to do with spending funds. We've found, primarily on the local level, that the bureaucratic purchasing and auditing process isn't structured to work well with long-term development projects where technology is a significant issue. The people who have the authority to approve or disapprove computer-related technical expenditures, may not have the expertise to evaluate the fiscal soundness of those expenditures. If the bureaucracy doesn't support or understand the technical concept, and focuses on the minutiae of project expenditures, then what results is that innovative technical design may be compromised in the vendor's need to fit an inflexible fiscal model.

Recommendations

Of relevance to the discussion of fiscal obstacles we've encountered in this project is a U.S. Public Health Service Report (R.D. Lasker, B.L. Humphreys, W.R. Brathwaite) which was distributed to participants of this conference in the registration packet. The report describes the National Information Infrastructure (NII) initiative and presents the results of an April, 1995 conference. One of the goals of the conference was for leaders of the National Information Infrastructure initiative to come together to discuss barriers to using NII technologies in public health. One of the five obstacles identified was "...organizational and financing issues that make it difficult to integrate information systems or bring potential partners together." While specific examples of these obstacles were not presented, the statement suggests that the fiscal and organizational problems we've encountered in this project are not uncommon to others who collaborate to develop information systems.

In order to feel comfortable with allocating fiscal resources for longer-term computerization projects, we suggest that funding for projects be evaluated after thoughtful consideration of the long-term benefits of the project, relative to the short-term costs of implementing it. We recognize the need for funding agencies to monitor the use of public funds, but suggest investigation of other funding approaches that will provide the fiscal commitment to develop long-term computerization projects, while still maintaining fiscal accountability.

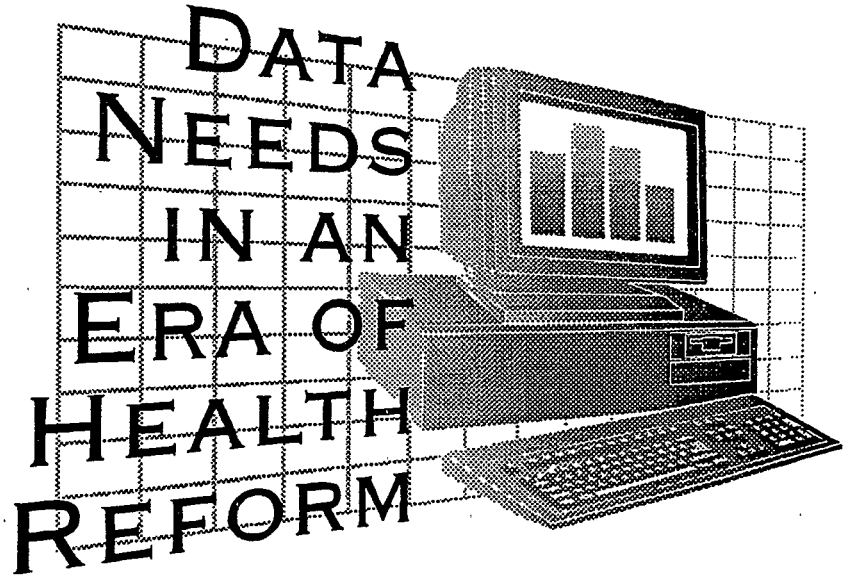
With regard to the second obstacle - spending funds, we suggest that some thought be given to developing financial accounting models on the local level which are more conducive to facilitating complicated, technical projects between public and private entities.

One of the recommendations that came out of the April, 1995 NII Conference was for state and local public health agencies to "Actively seek out partnerships and funding opportunities with health care organizations, medical informatics groups, and the commercial sector."

Before this can occur successfully, however, we need to define what it means to be a partner in these types of collaborative relationships which are encouraged on a national level, and develop fiscal systems on the local level which can be responsive to changes in the way the public and private sectors may work together in the future.

Session V

Melding Medical Care and Public Health



DEVELOPMENT OF A COMMUNITY-WIDE CLINICAL DATA BASE FOR CHILDREN'S PRIMARY CARE WITH PUBLIC HEALTH UTILITY

Larry Deutsch, Children's Health Network
Georgine Burke, Paul Gionfriddo

ABSTRACT

A wasteful schism exists between practices of record keeping in clinical medicine, and methods of data collection for fiscal and public health functions. Within each realm, fragmentation and duplication are rife. Wide community acceptance and sharing of a core data set requires consensus among diverse, perhaps competing, interests. The value of health information is enhanced by the ready availability of uniform data in varied contexts.

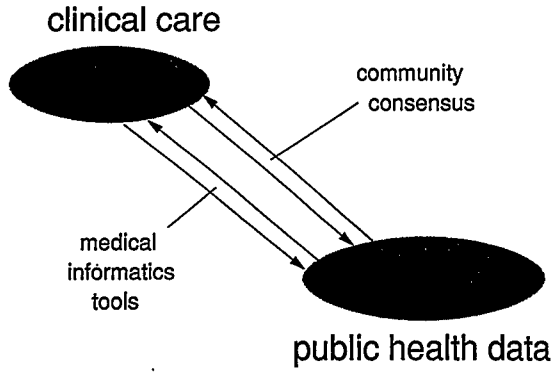
We describe a process to collect primary data on children's health status for surveillance, planning, and reform efforts through design and implementation of a comprehensive multifunctional clinically-driven data base among regional providers. In this Children's Health Network, a system has been developed for computerized linkages among heterogeneous providers serving inner-city families for whom multiple-site use is common. Its priority is the quality of primary care for this population, emphasizing integrated service and information in context of family and community, in accordance with a recent Institute of Medicine (IOM) redefinition.

The core data set is an enhancement of the National Committee on Vital and Health Statistics (NCVHS) definition of a Uniform Ambulatory Care Data Set (UACDS), enlarged for application to infants' and children's services, computerized with open-architecture design and modular capacity to permit multi-institutional exchange and to address special needs of individuals and subpopulations.

The data set is being developed to serve clinical and public health needs. A community-consensus process is being used to address the following data system needs: a) continuity and information-sharing across sites for high-quality clinical care, b) a value-adding format with intelligent features, guidelines, and on-line services, c) new benefits for families such as prompts and parent-held native-language records, d) testing of current confidentiality requirements and security techniques for electronic data sharing, e) automation of functions such as report generation, data analysis, and billing to achieve economies for providers and public agencies, and f) accumulation of longitudinal primary data for outcomes research and public health planning.

INTRODUCTION

Health care is at its best when both the practitioner and patient are well-informed. However, in many central urban and remote rural areas, information access is characterized by a lack of continuity and coordination among providers. In these areas, a local information infra-structure and a patient-centered system of primary care are missing. Individual and reference data are often lacking. Decision-making and follow through are hampered, with limited involvement of patients in planning their care, and insufficient aggregate data for cost analysis, outcome research, community health planning, and other purposes.



A Children's Health Network has been designed to extend current information technology to these underserved areas. Our approach to improving quality of individual care and controlling costs emphasizes use of computerized clinical information networks for better decision making and continuity, and, secondarily, for data aggregation for financial, research, and public health planning. This patient-centered approach is in distinction to a) data systems designed primarily for billing and administrative functions, and b) to cost-control efforts which rely on fiscal and managerial ("gatekeeper") mechanisms. A uniform data base among sites serving the same population will answer several clinical and public health needs.

INCONSISTENT CARE, POOR DATA

Too often, doctors and other providers labor with knowledge and dedication to improve health status at individual, institutional, or programmatic levels, but without broader awareness of how the welfare of an individual or community is affected by certain decisions or interventions.

How can we bring this systematic perspective to improve health conditions of infants and children, which in many urban and rural areas of the U.S. are far from optimal, and below that of many other countries? It is

clear by now that the presence of technology itself is not the answer. Deplorable and preventable health conditions are found within steps of our cities' technically-advanced medical centers.[1]

In inner cities and remote rural areas, well-publicized preventable conditions include lead toxicity, injuries, and certain behavioral disorders and infectious diseases. These issues are best addressed through good primary health care, as well as amelioration of community environmental and socioeconomic factors which contribute to these ills. The Institute of Medicine has recently re-defined primary care as

> *"the provision of integrated [comprehensive, coordinated, and continuous], accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."* [2]

In contrast, the experience of clinicians and families shows that health services often lack the elements of integration called for by the IOM, particularly the continuity of care and coordination of services required for adequate non-redundant evaluation, treatment, and follow-through. These failures are apparent in impoverished urban areas where the patient population uses multiple facilities - despite strong efforts to establish "medical homes." In Hartford, Connecticut, for example, the population is 1) mobile: 61% of housing units have been occupied by current residents for under 5 years; 2) multicultural: a majority of school children are of minority background, with a Latino plurality; 3) poor: 68% of the school population is Medicaid-eligible; and 4) have limited or inconsistent access: periods with or without employment and varying or no insurance coverage.

Ambulatory care facilities include community health centers, hospital out-patient departments (OPDs), school-based clinics, visiting nurse associations, and a few private practices. Among these facilities, children often lack a regular source of ambulatory care (RSAC), more so for poor than non-poor (15% vs 8%) in national survey data.[3] Those with RSAC made 80% timely routine care visits, versus 48% for those without one. Moreover, poor children in the national survey more often (17% vs 6%) received sick care at a site different from routine care, a discontinuity particularly for those with access to a community health center rather than a physician's office (40 vs 4%). For Hartford, 67% of those at an off-hours OPD clinic usually attended a different facility for care, including 22% indicating "none" for RSAC.[4]

These community sites operate with different hours, changing staffing, incompatible data systems, and conflicting priorities. Although these facilities serve largely one population, they have generally been unable, through lack of planning and financing, to organize and support comprehensive up-to-date information systems among themselves. Information transfer under actual conditions is primitive, with illegible carbons, late letters, incomplete phone messages, etc. This concretely impairs the thoroughness and effectiveness of dedicated and well-intentioned health providers.

Furthermore, data are institution- rather than patient-centered. Documentation is often non-uniform, serves primarily a billing function, and resides in distinct, single-function data bases (e.g., for lead monitoring, immunization status, nutrition or social service programs, specific disease entities). Without expensive and time-consuming labor, aggregation of the same data for multiple functions - longitudinal tracking for outcome research, utilization and cost analysis, public health program planning, and policy formation - is virtually impossible. In summary, infants and children are subject to well-understood health hazards and suffer impairment due to our unwillingness or inability to distribute and apply systematically the technical tools currently at hand.

PRIMARY CARE, CLINICAL INFORMATION SYSTEMS, AND COSTS

Lack of adequate systems for primary care in the United States leads not only to suboptimal health status reflected in local and national indices, but also to poor cost effectiveness. Cost savings related to particular improvements in primary care have been shown; good longitudinality (consistent caregiver, site, and record), for example reduces hospitalization, preventable illness, and overall costs of care.[5] Great savings result from regular use of community health centers and school-based clinics rather than emergency departments.

Cost benefits have also been shown with computerization of health records. In its important volume ***The Computer-based Patient Record: an essential technology for health care,***[6] the IOM records numerous areas, such as unnecessary or redundant laboratory testing, medication errors, and data entry inefficiencies, for which expenses have fallen using modern clinical and management information systems. Inclusion of on-line library reference services also reduces costs of patient care[7]. Demonstration projects with clinical information systems operating under real conditions are needed to measure cost-savings (as well as improved care quality and health outcomes) among large and small institutions serving community populations.[2,6,8] This system approach is distinct from a focus on case management, electronic billing, or utilization control. Research in linked clinical system models is pertinent to state and federal agencies, e.g. in the monitoring of Medicare and Medicaid programs if there is shift to managed care, and to private sector alliances.

In summary, a lack of communication and coordination frameworks utilizing current technology impairs health status and elevates costs. Creation of new local information infrastructures linked with statewide and national services will address some of these system failures.

METHODOLOGY

The Children's Health Network is a project conceived by numerous individuals and institutions concerned with improving the quality of health services for infants and children. It began with formation of a multi-disciplinary task force and developed with support from local foundations and the Maternal and Child Health Bureau (Health Resources and Services Administration, Public Health Service, Department of Health and Human Services). The task force formulated working groups addressing specific areas:

- content of shared uniform clinical data base;
- coordination among network sites;
- design of overall network architecture and software;
- legal research in emerging confidentiality standards and law to assure privacy of information and system security, and to recommend policies and procedures for participating sites;
- relationships with outside institutions and agencies seeking aggregated data for research and public health functions;
- evaluation of Network conception, functioning, utility, and user (provider and family) satisfaction.

The network design developed was an open-architecture PC-based distributed client-server system using Windows and a modern SQL relational data base.[9] Modular elements for particular diagnostic entities, disease states, artificial intelligence, graphical capabilities, and report generation may be added depending on provider interests and needs.

The system design anticipates flexible data entry techniques and multiple functions for its **demographic** (enrollment-based) and **comprehensive clinical** (encounter-based) information, expanding the proposed uniform ambulatory care data set (UACDS) with fields of pediatric importance (growth, immunizations, dental care, development, social services) and incorporating standards for data definitions and exchange among heterogenous institutions, as they emerge.

For single- or multiple-site use, the program through its relational data base and network connectivity is preparing to:

- give health providers on-line access at each encounter to summary patient information, including demographic, medical and risk-factor data; to assist decision-making and document treatment plans; and to permit follow-through including automated prompts, record transfers, and outreach for active health assurance and prevention programs;
- accumulate longitudinal patient-level data summarizing conditions and interventions (medical and social) for medical treatment effectiveness studies and other research;
- enable providers to receive from and report to various specific data bases, fiscal organizations, and public agencies.
- accommodate new roles for patient/family participation in health care, with personal (hand-held) records in native-language translation and patient education materials;
- allow reporting of aggregate data for local community health monitoring, including small-area analysis, needs assessment, surveillance for specific entities, and discovery of trends, program assessment and resource allocation, public health planning and policy formation;
- meet emerging requirements for quality assurance (QA), and for utilization and cost monitoring with managed care or other frameworks, including Medicaid (indigent) populations.

Pilot sites for the Children's Health Network project include a paired elementary school health clinic and nearby pediatric ambulatory care center in a major urban hospital in Hartford, CT. Additional linkages are planned (Fall, 1995) for a community health center and high school health clinic in Hartford, and different clinics and practices in New Haven and other cities.

PUBLIC HEALTH SYSTEMS AND BARRIERS TO COMMUNITY INFORMATION NETWORKS

Several barriers have been identified in applying a U.S. National Information Infrastructure to public health. These include: the need to protect privacy of health data; the lack of national data collection and maintenance standards; insufficient understanding of applications of NII technology to public health; and lack of experience in the public health workforce with NII technology.

The Network has benefitted from development by the NCVHS of its core data set (UACDS). In adopting its sixteen fields as a starting point, the Network hopes that its data will be comparable to others around the country, enabling researchers and policy makers to compare different populations. By creating additional fields, the Network has sought to

meet the needs of local children's clinicians and institutions to have more complete and portable medical records.

Considerable effort has been devoted to development of policies and protocols to protect the confidentiality of patient-specific data while allowing information exchange among clinicians. Procedures have been developed for transfer of records only when informed consent from parents has been entered, protection of data at a site when no consent has been documented, and policies for aggregate data use for public health purposes.[10,11]

The Network has worked to reduce cost barriers to computer-based records by designing a distributed system using low-cost personal computers with Windows and a common data base software. With ongoing training of providers and easy-to-use formats for data display and report generation, system users may become familiar with its operation in a short time.

Finally, while the Network was designed to improve continuity and quality of care through more efficient information exchange, it is intended that data residing in the system will provide valuable information for public health activity, including outcome research, program evaluation, and policy making. In building such a multifunctional system, it has benefitted from Maternal and Child Health Bureau (PHS) support.

POLICY IMPLICATIONS

With the IOM criteria for primary care in mind, a traditional model is the old-style family practitioner, rooted in community, personally familiar with individual and family, available all the time without financial, language, bureaucratic, or other barriers, acting as patient advocate and care coordinator (rather than "manager" or "gatekeeper"), able to make intelligent use of additional local or distant facilities and information when warranted and receive feedback from colleagues and local institutions for continuity of care. But times have changed. Current models of primary and preventive health practice in inner city and rural areas stress community-oriented primary care (COPC) and support for community health centers and school-linked health services, as well as health maintenance organizations and wider fiscal-administrative networks or alliances for managed care. Discussion of these is beyond our scope. Some models may recognize the need for patient-centered computer-based records and improved aggregate data.

A major focus of policymakers' attention in these times must be proactive extension of current and new information technology to smaller community-based primary care providers - those on the front line of health care delivery, particularly to underserved populations. This is in keeping with concepts presented by Vice President Gore to ensure access for all communities to the information superhighway; and it is concretized in new programs through the National Library of Medicine, Agency for Health Care Policy and Research, Office of Rural Health Policy, and the National Telecommunications and Information Administration.[12] Assistance to these community institutions should emphasize patient-centered computer-based record systems with uniform minimum data bases and security features. Systems should allow adaptability for local needs and reporting requirements, integration of legacy systems, and linkage to local and regional networks which in turn are joined to the national information infrastructure. Policies may include:

- sustained funding of smaller primary care institutions including community health centers, school-based clinics, and home-visiting services, and their integration into community health information networks (CHINs) or other regional information infrastructures;
- investment in a variety of community-based demonstration projects which model clinically-driven information systems yielding multifunctional aggregate data; these systems are distinct from - neither exclusive of nor equating to - management information systems which rely on fiscal and managerial ("gatekeeper") mechanisms for control of costs;
- for all primary care providers, availability of standard, flexible, regularly-revised public-domain software, including programs to meet burdensome newly-emerging requirements for quality monitoring, fiscal and agency reporting, etc.
- provision and maintenance of networking equipment including linkage hardware, fiber optic or other secure line connections, connectivity fees, conversion software to accommodate new and legacy systems, and stand-alone versions for remote or non-networked institutions;
- expansion through local networks of on-line cost-free reference services through the National Library of Medicine and regional academic medical centers;
- on-going technical assistance through state or federal sources to the many sites lacking expertise (information departments) internally, especially to meet new quality monitoring and reporting requirements and adapt to technical advances.

There are many implications of comprehensive primary care systems such as the Children's Health Network that relate to problems confronting clinicians, payers, and policy makers in the 1990s. The Network's development and findings will be beneficial to others engaged in similar efforts.

ACKNOWLEDGEMENT

This work is supported by Project # MCJ-097112, Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Public Health Service, DHHS.

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A COMPUTERIZED HEALTH AND EDUCATION PASSPORT FOR CHILDREN IN FOSTER CARE

Suzanne P. Lindsay, Children's Hospital

Paper not available for publication

MEASURING DISABILITY WITH PARSIMONY

Lois M. Verbrugge, University of Michigan
Susan S. Merrill, and Xian Liu

Introduction

Disability is a multifaceted phenomenon. Health-related limitations can occur in numerous roles and activities, such as job, personal care, household management, socializing with friends, active recreation, and passive leisure. There are also various dimensions of those limitations, such as degree of difficulty, use of equipment or personal assistance, pain while engaged in the activity, and satisfaction with performance. Faced with such diversity when designing surveys, researchers select certain activities and dimensions that seem most germane for the age-gender groups studied or for public policy. The most common choices are questions about difficulty or assistance in performing personal care (ADL), household management (IADL), and job activities. Even with this restricted scope, the number of disability questions in surveys has become large, posing burdens for interviewers, respondents, survey analysts, and disability statistics users. And pressures continue for still further expansion of disability items.

In distinct contrast to this situation, there has been movement toward parsimony in measuring morbidity. Although health status is also multifaceted (presence/absence of specific conditions, severity, duration, etc.), a global item to summarize it is routinely included in surveys: self-rated health. Its value for prediction of dire outcomes such as institutionalization and death is equal to or better than arrays of detailed morbidity items. The item is brief to administer and has good colloquial merit ("makes sense" to respondents). In short, one question about health happens to be realistic, comprehensive, and prescient.

The sharp difference between survey approaches to disability and morbidity is the underlying motivation for this paper. For all the interest in and wide use of a global morbidity item, there has been little work to develop and use a *global disability item*. It may indeed be possible to find one that has strong analytic value and also captures the real-world experience of disability well. If so, it should be regularly included in health surveys either as a companion to detailed disability questions (in surveys with extensive focus on chronic morbidity and functioning) or by itself (in surveys with sharp time limits or brief coverage of morbidity/functioning). Alternatively, it may be possible to *reduce the number of detailed items* about disability by dropping some activities or dimensions, with little loss of analytic value. Either approach--a global item or reduced items--will achieve disability parsimony, but the global item is certainly most economical.

This paper has four parts: First, we provide some background for thinking about disability measurement and the issue of parsimony. Second, we present empirical results from three projects; one relates chronic conditions to a great number of *detailed* disability items, and the others relate a *global* disability item to detailed ones and to self-rated health. Third, from the results we draw conclusions about (a) how detailed disability items can be culled and (b) whether global disability is worth adding to surveys. Lastly, recommendations are offered about work that can be done with existing surveys or in small-scale laboratory-based studies to promote compact questioning of disability in health surveys.

Background on Global and Detailed Disability Items

Disability refers to the impacts health problems have on people's social functioning, that is, their ability to perform roles and activities (Pope & Tarlov, 1991; Verbrugge & Jette, 1994). "Social functioning" includes the whole range of typical and personally-desired activities an individual does, ranging from the most basic and universal (such as eating and dressing) to the most discretionary and distinctive (such as a person's favorite hobby or recreation). Disability can be short-term or long-term, and it can be due to acute or chronic conditions. Because research and policy interests are typically on long-term dysfunctions associated with chronic conditions, that is our focus here.

The aim of a *global disability* item is to measure overall social functioning briefly but well. It must refer to protracted, health-related difficulties in a large span of activities. The question format can be one single question, a branch-and-stem item (main question plus probes about duration and health-relatedness), or a small set of questions (short ones that are combined into a single variable during analysis). These formats are compact in the questionnaire itself, and thus brief to administer and easy to analyze.[1]

There are some examples of global disability items in contemporary U.S. and Canadian surveys (Verbrugge, 1994). Most have been created through a mixture of judgment and consultation, copying from prior surveys, and pretesting. Ideally, choices should be based also on empirical evidence about content (what aspects of disability the item covers) and analytic value (relationships to predictors or outcomes). Little evidence of that sort exists. So good craftsmanship is the mainstay for designing items.

What sorts of methodological work can help in evaluating global disability items? There are two basic approaches: cognitive and statistical. Cognitive approaches are well suited to studying the processes that respondents use to think about questions and come up with answers. These studies are usually small-scale and often laboratory based. Statistical approaches are used on moderate-to large-scale data sets to study multivariate item structure, reliability, and concurrent and predictive validity. Examples of analyses that can inform us about global disability are (1) relationships between a global item and specific disability items, to determine the global item's included and excluded content, (2) relationships between global disability and global morbidity, to see if they are non-redundant, (3) models relating chronic conditions and global disability, to assess its health-relatedness, and (4) the prediction ability of global disability by itself (apart from self-rated health) on subsequent outcomes. In general the evidence compares and contrasts global disability with (a) detailed disability items and (b) global morbidity. Ideally, one wants a global disability item to have good coverage of detailed disabilities (high correlations with them) and be distinctive from self-rated health (moderate-to-low correlation and strong net relationship to outcomes).

The notion of parsimony is also relevant for surveys that contain *detailed disability* items, the current situation for contemporary health surveys (especially of older persons). The numerous disability questions are usually about a rather narrow set of activities (ADLs, IADLs, job; also physical and sensory limitations), with several dimensions for each (difficulty, equipment assistance, personal assistance). Parsimony could be achieved by reducing the number of detailed items. Statistical approaches can inform us on this issue; for example, analyses of (5) relationships between chronic conditions and specific disabilities, to assess whether disabilities have similar morbidity precursors, (6) how detailed items predict prospective dire outcomes, and (7) clustering and

hierarchy of items, assessing if any given detailed question actually represents a whole disability profile. Items with low health-relatedness or low prediction can be considered for elimination. If scaling analyses show strong hierarchy, then an economical approach to asking about disability can be considered (items are ordered according to the scale, questioning begins somewhere in the middle, and it proceeds 'up' or 'down' the scale until a yes for disability occurs).

We now present results of three projects motivated by our interest in parsimony. One studies the health-relatedness of numerous *detailed disability* items (#5 above). The second and third study relationships of a *global disability* item to detailed disabilities (#1) and self-rated health (#2). The second project also considers the global item's health-relatedness (#3). We make conclusions about winnowing detailed items and about the merits of a global item. The next three sections discuss the projects, one at a time.

Morbidity Precursors of Detailed Disabilities (Project 1: AHEAD)

Are chronic conditions strongly related to presence and degree of disability, or only weakly so? Are the links between morbidity and disability distinctive (different chronic conditions are implicated for each disability) or nondistinctive (the same conditions come into play for virtually all disabilities)? The answers will indicate the health-relatedness of dysfunctions and similarities in morbidity-disability relationships.

We utilized data from the AHEAD Survey (Asset and Health Dynamics of the Oldest-Old) Wave 1 (Merrill & Verbrugge, 1995). AHEAD is a population-based sample of U.S. community-dwelling persons ages 70+ at Wave 1 (1993-94); n=8,224. The questionnaire has information on presence/absence of 25 chronic conditions, 22 specific disabilities (ADLs, IADLs, physical limitations;[2] with various dimensions: degree of difficulty, use of assistance, need for assistance, pain when doing activity, tiredness when doing it, long time to do it), and 9 productive activities. The disability items were used as is and also in aggregated forms (such as "any ADLs" and "sum of ADLs"). The full set of chronic conditions (X) were related to each disability outcome (Y) by logistic and linear regressions, controlling for age and gender.

Descriptive statistics for variables and tables with results are in Merrill and Verbrugge (1995). Three tables most pertinent to this article are available on request: One illustrates results for detailed disability (the table is for physical limitations), the next illustrates results for aggregated disability (the table is for sums), and the last lists chronic conditions that always/almost always have significant relationships with disability items.

1. The most striking result is that the same 8 chronic conditions routinely have statistically significant associations with the many disability items (detailed and aggregated). They are stroke, diabetes, arthritis, hip fracture, urinary incontinence, poor vision, frequent pain, and a residual "other conditions".[3] The other chronic conditions are related to certain disabilities or disability domains, but not consistently across the board.

2. R^2s are generally .10-.20 for specific ADLs and IADLs, and .20-.30 for specific physical limitations. Aggregated variables (such as any ADLs and sum of ADLs) produce higher R^2 than their detailed source items, the increase being about .10. Moreover, more chronic conditions have significant relationships with these aggregate items than with the detailed ones.

The results lead to two conclusions: (1) First, there is plenty of redundancy in the health-relatedness of disability items. Thus, if a survey needs to include the topic of disability but does not really need disability details, then any 4-5 items will serve that purpose adequately. The most sensible choice is asking one dimension (such as difficulty) for several diverse activities (spanning ADLs, IADLs and physical limitations). (2) Second, the association between morbidity and specific disabilities (R^2) is modest, but increases notably for aggregated disability variables. Thus for analytic parsimony, one should use the aggregates and skip the detailed items. But there is no fieldwork parsimony in this approach, since aggregate variables depend on having asked the plethora of detailed items! In short, the AHEAD analyses suggest how to use detailed items with parsimony in two ways: by reducing the number of detailed items placed in a questionnaire or, if that doesn't happen, by reducing the number of disability variables analyzed.

Distinctive Features of Global Disability (Project 2: HRS)

Is global disability related to all specific disabilities, or to some specific ones far more strongly than others? Is global disability closely related to global morbidity (self-rated health) or weakly? How health-related is global disability? The answers will indicate how well a global item compasses activity domains, whether it is really something different from global morbidity, and how well it reflects underlying health problems.

We utilized data from the HRS (Health and Retirement Survey) Wave 1.[4] HRS is a population-based sample of U.S. community dwellers ages 51-61 in 1992, plus their spouses; n=12,654. The questionnaire has information on disability (limitation in job, housework, or other activity, 5 ADLs: and difficulty doing each, 5 physical limitations: any difficulty doing each; no IADLs asked) and health status (presence/absence of 19 specific conditions, self-rated health).

We used the limitation in job/housework/other items to create a global disability variable, as follows: All persons are asked if they have an impairment or health problem that limits the kind or amount of paid work they can do. The subset saying no are asked about health-related housework limitations; and lastly, the further subset saying no to housework are asked about health-related "limitation in any way in activities". Our global variable is dichotomous, scored 1 if yes to any of the three items, 0 otherwise.[5] The percentages are 29.5% disabled and 70.5% non-disabled. (The building-block percentages from the three items are: 21.5% job limitation, additional 3.5% housework limitation, additional 4.5% other limitation.) The other disability items were used as is and also in aggregated forms (such as "any ADLs" and "sum of ADLs").

For the first part of the analysis, detailed disabilities (X) are related to global disability (Y) in logistic regressions. For the second part, aggregate and global disability (X) are related to self-rated health (Y) in logistic regressions. Lastly, we are able to look again at the health-relatedness of disability, this time with a genuine global disability item. Age, gender and education are controlled in all regressions.

Descriptive statistics for variables are available on request. Four tables (referenced at suitable points below) are included with this article.

1. How are detailed disabilities associated with the global indicator (TABLE 1)? Three models were estimated: with both physical limitations and ADLs as predictors (Model I), just ADLs (Model II), and just physical limitations (Model III). On their own, physical limitations are strongly linked with global disability (Model III). Each item (walk blocks, climb stairs, pull/push large objects, lift/carry ten pounds, pick up dime) has a statistically significant coefficient for the total sample and each gender. Similarly, difficulties in ADLs (walk across room, bathe,

transfer in/out of bed, dress; but not eating) are also associated with global disability (Model II). But in models with combined predictors (Model I), the ADL coefficients fade in size while those for physical limitations remain essentially as large as before. Log likelihood values show this relative importance as well; ADLs add almost nothing to the prediction strength of physical limitations (comparing Models III and I).

2. The relationship of disability to self-rated health was studied next (TABLE 2). Self-rated health is scored in two ways, as a dichotomous variable of poor vs. other responses(fair, good, very good, excellent) and a dichotomous variable of poor/fair vs. good/very good/excellent. Only 8.0% of this middle-aged sample report poor health; 14.3% report fair health. Results show that our models (with straightforward morbidity and sociodemographic predictors) do a better job predicting fair/poor health than poor health--not surprising given the rarity and thus "unusual circumstances" underlying poor health at these ages. Of the three disability variables, global disability has the strongest relationship to self-rated health; this is seen both in coefficients and log likelihood values.

3. Lastly, we studied relationships of chronic conditions to detailed, aggregated, and global disability. The results are surprising and welcome: Chronic conditions are excellent predictors of global disability, more so than for aggregated disability (TABLE 3) and much more so than for detailed items (TABLE 4). This extends and replicates the AHEAD results (which showed that aggregated items were better than detailed ones). On this basis, we can state a hierarchy of health-relatedness for disability variables, with global disability ranking best of all. Stroke, heart disease, and psychiatric problem are the strongest predictors of global disability. Stroke also proved consistently strong in the AHEAD results.

We arrive at three conclusions: (1) First, physical limitations are the foundation for disability in midlife. ADL difficulties are not very common at these ages, but even so, their presence is much less predictive of global disability than are physical limitations. Stated another way, generic functional problems are more implicated in general disability status than any specific disabilities are. This might strike some readers as odd--the global item is more closely related to its precursors than its components. Whether this result holds up in older samples and in data sets with larger arrays of physical, mental, and social functioning items remains to be determined. (2) Second, there is sizable overlap between global disability and global morbidity. This result was expected. Our analyses are very simple, and a firmer judgment of what "sizable" really means would come from models using both global disability and global morbidity as predictors (X) of concurrent or prospective outcomes (Y). Because global items are rare, we found no example of such analysis in the literature; there are examples with multiple or aggregated disability items as predictors. (3) Third, global disability is far more health-related than are activity domains (ADLs, physical limitations) or detailed activities. This is a welcome result; its strength surprised us.

A Genuine Global Disability Item (Project 3: BRFSS)

A global item about disability was included in the 1993 Behavioral Risk Factor Surveillance System Survey (BRFSS): "During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?" (Answer range is 0-30.) BRFSS is a telephone survey of adults (ages 18+) in all 50 states. Four general items about health and disability were introduced in the 1993 Core and have been continued since then (Hennessy, Moriarty, Zack, Scherr, et al., 1994; Centers for Disease Control and Prevention, 1994). The 1993 survey also had a special module on Activity Limitations, with detailed questions about limitations in job, housework, personal care (ADLs), routine needs (IADLs), and any other activities. In 1993, 102,464 persons responded to the Core; for analyses we use a 20% sample (cases deleted if missing data for age and disability), n=20,029. The activity limitation module sample is 12,843.

In contrast to HRS, BRFSS gives us a genuine global item to study. The majority of persons (81.3%) report no disability days; there is no difference by gender, and the percent rises only slightly across age groups. Among persons with disability days, the distribution is very skewed with reports clustered at just a few days (1-3 days; 47%) or else all 30 days (15%). This suggests that the item picks up both short-term and long-term disability.

Further descriptive statistics and tables with analytic results are available on request. One table is included with this article. A paper is in preparation for journal submission.

1. How are global disability and self-rated health related? The bivariate relationship is moderately strong and in the expected direction (the more disability days, the worse self-rated health). The correlation is .35 when we use 0-30 disability days, and .55 for 1-30 disability days; thus, having some disability days is more indicative of health status than 0 days (which can occur for both well and ill persons). We computed logistic regressions with self-rated health and sociodemographic/behavioral factors as predictors of global disability (0 vs 1+ days). Global health's association with global disability diminishes greatly, both in odds ratios and explained variance (TABLE 5).

2. Which activity limitations (job, housework, ADL, IADL) are well-represented in global disability? We used cross-tabulations to evaluate these associations. The global item was split 0 vs 1+ days (none vs any), and then also 0-9 vs 10+ days (none/short-term vs long-term disability). Relationships prove to be much stronger with the second variable, as we expected: The activity limitations refer to long-term disability, and the 0-9 vs 10+ split of disability days captures that far better than the 0 vs 1+ split. Associations between global disability and job limitations (esp. being unable to work at all due to health), housework limitations, and IADL limitations are very high. The association with personal care is strong for ages 70+ (but only moderate for ages 18-69). Compared to these, associations with limitation in any-other-activity are weak.

3. Parallel cross-tabulations of the activity limitations with self-rated health were produced. The associations are quite similar to those above (with global disability). With this exception: Needing help for personal care or routine needs is more strongly related to disability days than to self-rated health. Stated simply, dependent persons have many disability days.

We come to three conclusions: (1) First, once personal characteristics associated with both are taken into account, we see that global disability is distinctive from self-rated health. That is reassuring, given the less certain findings from HRS on the matter. (2) Global disability reflects underlying specific disabilities very well. It should, and we are pleased the data verify that. The only exception is limitations in "any other activities"; this is a vague question for which Yes probably means many idiosyncratic things. (3) Both global disability and global health reflect activity limitations, but global disability is definitely better in reflecting ADL and IADL dependency.

Conclusions

Integrating the analyses above, we come to these conclusions:

1. Detailed Disability. Plenty of detailed items are appropriate in surveys if every single one of them has a scientific or public policy rationale. Each one will be analyzed on its own at some

point to fulfill those initial purposes. But for more general analyses of the data, aggregated variables such as "any ADLs" or "sum of ADLs" have better analytic yield. (In our AHEAD analyses, this specifically meant stronger health-relatedness.)

In many population health surveys, there is no good rationale for having numerous detailed items on disability. Will just a few do, and which ones? The AHEAD results suggest that the many specific ADLs, IADLs, or physical limitations have similar relationships to chronic morbidity, so choosing any small set of them will suffice to represent disability. This is acceptable for a cross-sectional survey setting. In a longitudinal setting, prediction ability as well as health-relatedness must come into the winnowing decision. One needs to know from prior studies if detailed items have similar prospective prediction, or not.

2. Global Disability. A global disability indicator reflects the disablement process very well. The HRS results show that it has stronger relationships to causal precursors (chronic conditions and physical limitations) than detailed disability or aggregated disability variables do. That is a 'plus' in its favor. But global disability has strong overlap with global morbidity (self-rated health). The extent of overlap needs more explicit study by comparing the two items' strength as predictors of concurrent and prospective outcomes. At issue is the net effect of global disability, controlling for self-rated health.

The HRS indicator is oddly constructed and not ideal; the component items were not designed with their pooling into a global item in mind. Nevertheless, the indicator is analytically sturdy, showing distinctive and systematic results when compared with detailed disability, aggregated disability, and self-rated health. We have no doubt that overtly designed global items will do as well--and likely better.

This proves true with the BRFSS item, which was designed to be a global indicator. Results show that it does a very good job in capturing specific disabilities. We prefer a global item aimed explicitly at long-term disability (the BRFSS item is worded to include both short- and long-term) and expect such an item to show even better results, that is, still closer coverage of detailed limitations.

Recommendations

Some recommendations for research and questionnaire design that spring from our work are offered:

1. Recommendations for Research. What research can be done, economically and soon, to further the goal of parsimonious questioning about disability? We make four recommendations:

(1) Existing data sets with numerous detailed items can be analyzed, studying closely item correlations and scaling characteristics. The motivation for the work is not just psychometric analysis but practical decision-making about (a) items that can be dropped or (b) efficient questioning strategies in an ordered series of items.

(2) With imagination, global indicators can be generated from existing data sets. Many surveys now have series of activity limitation questions which can be pooled into a single variable (as NCHS routinely does for the National Health Interview Survey). Or, numerous detailed items can be pooled into an "any disability" variable. The analytic merits of these pooled variables can be compared with detailed items.

(3) Surveys with genuinely global items are few and far between, but the search should be made and opportunities exploited. We are currently analyzing data from the CDC Behavioral Risk Factor Surveillance System survey (BRFSS), which included global morbidity and disability items for the first time in 1993. We also note the two Health and Activity Limitation Surveys conducted in Canada (HALS) and the 1994-95 Disability Supplement for the National Health Interview Survey in the U.S. (NHIS-Disability); we leave their analytic potential to readers' scrutiny.

(4) Global items can be crafted and then evaluated for colloquial sense and content in laboratory settings. A crucial aspect of this work is to determine the best place for the two essential qualifiers (disability is protracted and health-related).[6] Nonverbal formats such as the COOP chart of Daily Activities (Beaufait, Nelson, Landgraf, Hays, Kirk, Wasson, et al., 1992) should be considered and tested in conjunction with verbal ones.

2. Recommendations for Survey Design. What can be done immediately, without additional research information, when designing surveys?

(1) Every survey that includes self-rated health should also include a global disability item. The briefest rationale is that "functional status is just as important as health status". Items used in other surveys to date are shown in Verbrugge (1994), and good candidates are noted for consideration in future surveys. They are appended here as Figure 1.

(2) If detailed items are needed, every one should have excellent rationale and conceptual integrity. Its analytic use should be known in advance (if it doesn't exist, neither should the item). The conceptual niche that each holds should be stated clearly. Further, overall coverage of the concept "disability" should be considered afresh when a survey is designed. This means resisting the pressures, which are very strong, to repeat items used in other surveys. For example, if n questions are desired, surveys can have better coverage of the disability experience by asking about more activity domains and just one dimension, in contrast to contemporary practices of asking about few domains and several dimensions.

Summing up, the goal is to measure disability in comprehensible, comprehensive, veridical, and useful ways in health surveys. We think it can be done with more parsimony than now exists.

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Table 1. Effects of Specific Disability Items on Global Indicator, Logistic Regression: American Adults

Explanatory variables	Model I	Model II	Model III
ADL items			
Walk	0.685	2.343	
Bathe	0.944	2.281	
Transfer	0.697	1.807	
Eat	-0.918	0.384	
Dress	0.794	1.488	
Physical limitation items			
Walk several blocks	0.964	1.045	
Climb several stairs	0.704	0.869	
Pull/push objects	1.214	1.277	
Lift/carry 10 pound	0.945	1.024	
Pick up a dime	0.398	0.569	
Intercept	-2.829	-2.353	-2.762
Log Likelihood	4058.03	2063.80	3985.42
Sample size	11972	12429	12035

Table 2. Association between Global Health Indicator and Global Disability Indicator

Explanatory variables	Model I	Model II	Model III
	Poor self-rated health		
ADL indicator	2.626		
Physical limitation		2.911	
Global disability			3.455
Intercept	-1.936	-2.623	-2.589
Log likelihood	1646.52	1434.72	2250.01
	Poor/fair self-rated health		
ADL indicator	2.318		
Physical limitation		2.026	
Global disability			2.418
Intercept	-0.791	-0.861	-0.707
Log likelihood	2350.69	2542.08	3565.42
Sample size	12443	12053	12598

Table 3. Effects of Specific Chronic Conditions on Three Disability Indicators

Explanatory variables	ADL indicator	Physical limitation	Global indicator
Hypertension	0.113	0.310	0.211
Diabetes	0.681	0.644	0.568
Cancer	0.386	0.360	0.652
Lung disease	0.301	0.756	0.731
Heart disease	0.269	0.725	1.012
Stroke	1.102	0.878	1.533
Psychiatric problem	0.423	0.463	0.821
Arthritis	0.687	0.380	0.586
Kidney disease	0.394	0.284	0.492
Other diseases	0.561	0.483	0.625
Intercept	-3.604	-2.376	-2.919
Log likelihood	2141.77	3176.14	4119.18
Sample size	12091	11711	12245

Table 4. Effects of Specific Chronic Condition on Three Disability Items

Explanatory variables	Climb stairs	Pull/push objects	Lift/carry 10 pounds
Hypertension	0.367	0.151	0.257
Diabetes	0.593	0.451	0.434
Cancer	0.264	0.418	0.362
Lung disease	0.829	0.504	0.539
Heart disease	0.632	0.740	0.669
Stroke	0.673	0.836	0.928
Psychiatric problem	0.341	0.485	0.444
Arthritis	0.505	0.322	0.236
Kidney disease	0.308	0.201	0.349
Other diseases	0.476	0.495	0.456
Intercept	-2.849	-3.000	-3.724
Log likelihood	2752.55	2863.12	2861.37
Sample size	12114	12093	12119

Table 5. Logistic Regression of Self-Rated Health and Risk Factors on Disability Days (0 vs 1-30)

	Model I		Model II		Model III	
	Beta	OR	Beta	OR	Beta	OR
Self-rated Health:						
Very Good	.57	1.8			.22	1.3
Good	.77	2.2			.47	1.6
Fair	1.53	4.6			.82	2.3
Poor:	2.74	15.5			1.59	4.9
Age (# yrs)			-.003	1.0	-.01	1.0
Gender			-.04	1.0	-.04	1.0
Education			-.001	1.0	.07	1.1
Working			-.28	.8	-.20	.8
Retired			-.31	.7	-.30	.7
Income			-.09	.9	-.03	1.0
Insurance			.16	1.2	.18	1.2
Married			.08	1.1	.09	1.1
White			-.19	.8	-.13	.9
Black			.08	1.1	.10	1.1
Hispanic			-.04	1.0	-.03	1.0
Body Mass Index			-.0001	1.0	-.001	1.0
Diabetes			.39	1.5	.21	1.2
High Blood Pressure			.22	1.3	.13	1.1
Alcohol Use (any)			-.02	1.0	.02	1.0
Mental Health Disab Days			.92	2.5	.86	2.4
Physical Health Disab Days			2.56	1.9	2.43	11.4
Current Smoker			.06	1.1	-.01	1.0
Former Smoker			.13	1.1	.10	1.1
Log-likelihood	221305383		861032406		892200790	
R^2	.07		.28		.29	

Figure 1. Candidates for a global disability indicator

1. National Population Health Survey, Canada

'The next few questions deal with any health limitations which affect ...'s daily activities. In these questions, 'long-term conditions' refer to conditions that have lasted or are expected to last 6 months or more'.

'Because of a long-term physical or mental condition or a health problem, are you limited in the kind or amount of activity you can do:

At home?
At school?
At work?
In other activities such as local travel, sports or leisure?'

For each: yes, no

Note: Canada has used global disability items in its population census and in national surveys such as the Health and Activity Limitation Surveys 1986-87 and 1991 and the National Population Health Survey 1994-95. The items have been very similar, with a little modification from one census/survey to the next. We show the

contemporary item but alter the descriptor for other activities from 'such as transportation to or from work or leisure time activities' to 'such as local travel, sports or leisure', a close reprise of what appears in some of the prior surveys.

2. New (developed by author)

'Because of a physical, mental, or emotional condition, are you limited in doing your daily activities like personal hygiene, house or yard care, shopping, your work, or other things you need to do?' Yes, no

If yes: 'Has the limitation lasted for at least 6 months or is it expected to last that long?' Yes, no. If yes to 6+ months: 'Are you limited just a little, somewhat, or a great deal in your daily activities?' Just a little, somewhat, a great deal.

Note: The item covers many domains, has a six month reference period for disability, and has severity gradations.

3. Modified from a pilot study on subjective health

'Is there anything about your health that makes it hard for you to do your usual activities?' Yes, no.

If yes: 'Has the difficulty with your activities lasted 6 months or more, or do you expect it to last that long?' Yes, no.
If yes to 6+ months: 'What are the activities you have trouble doing because of health?' Interviewer records responses.

'Would you say your difficulty doing these activities is a little, some, or a lot?' A little, some, a lot.

Note: The item is modified from a small-scale pilot study conducted by Charles Cannell and colleagues for the National Center for Health Statistics in 1975. We simplify the lead question, add the reference period for disability, and use different severity gradations.

4. Modified from National Health Interview Survey Disability Supplement, United States, 1994-95

After specific questions about physical conditions, if yes to any:

'During the past 12 months, did any of these problems seriously interfere with your ability to work or attend school or to manage your day-to-day activities?' Yes, no.

After specific questions about cognitive and emotional problems, if yes to any: (same question)

Note: The supplement accompanies the 1994-95 National Health Interview Survey (NHIS). It has two phases: phase one occurs at the same time as the NHIS Core and has disability questions about all household members; phase two is conducted several months later for persons who screen in from phase one as having disabilities. Here, we use a phase one item about emotional/cognitive problems, adding a parallel one about physical problems.

5. Modified from the Baltimore Longitudinal Study of Aging Followup 1

'Would you describe your overall level of functioning in your home, work, and leisure activities as: excellent, very good, good, fair, poor, don't know?' Excellent, very good, good, fair, poor.

Note: The Baltimore Longitudinal Study is a life-long study of adults conducted by the Gerontology Research Center, National Institute on Aging. Participants have medical exams and questionnaires every two years. The Follow-up was conducted in 1989 on dropouts, people who had not returned for the biennial exam. We modify the item by adding the descriptor 'in you home, work and leisure activities' and including the category 'very good' (to match the five response categories-excellent, very good, good, fair, poor-now used for self-rated health items in the US). This question must be asked in the context of health/functioning; without that context, "functioning" is vague.

Lois M. Verbrugge is a Distinguished Research Scientist, Susan S. Merrill is a Postdoctoral Fellow, and Xian Liu is an Assistant Research Scientist at the Institute of Gerontology, University of Michigan, Ann Arbor, MI. This article extends the analyses and text of a prior presentation, published in the Proceedings of the Sixth Conference on Health Survey Research Methods (Breckenridge, CO), June, 1995.

Footnotes

[1]We distinguish them from two other formats: (1) An aggregated item adds up the number of specific disabilities. This is analytically compact, but not compact in the questionnaire itself. (2) A short-form instrument covers multiple diverse concepts about health and functioning with about 5-20 questions total. By contrast, a global indicator covers just one concept.

[2]Conceptually, physical limitations are aspects of functional limitation, not disability (Verbrugge & Jette, 1994). For sake of economy, this is not emphasized in the paper.

[3]Questionnaire items for determining presence/absence vary for the conditions; for example, physician diagnosis of condition, own statement about presence of condition, symptoms in past year. Details can be found in AHEAD documents (it is a public-use data set) or the manuscript cited.

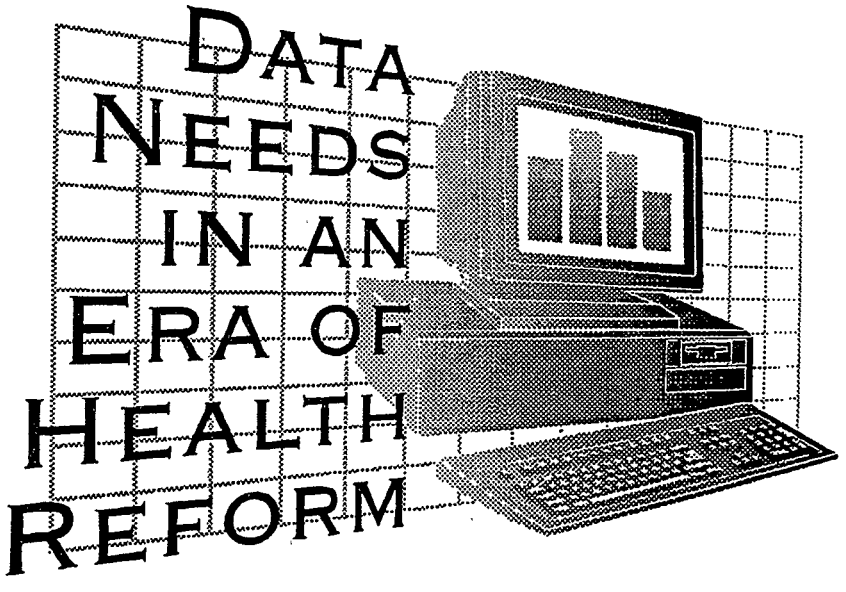
[4]The HRS analyses were conducted by authors Verbrugge and Liu.

[5]Because of the sequential questioning, the two items on housework limitations and other-activity limitations cannot be analyzed on a whole-sample basis, and prevalence rates for them cannot be estimated from HRS.

[6]The several options are to place these qualifiers in an initial preface (asking respondents to think about long-term health-related problems in the following questions), in each question, or in Follow-up probes (checking about duration and health-relatedness after respondents say yes to the disability question). Which approach achieves and maintains the desired focus without excessive verbiage?

Session W

Meeting the Needs of Special Populations



APPROCHES FOR IMPROVING ASSESSMENT OF THE HEALTH NEEDS OF SPECIAL POPULATIONS (MINORITY pOPULATIONS ESPECIALLY)

Emmanuel A. Taylor, M.Sc., Dr.P.H.
Centers for Disease Control and Prevention (CDC)
Elizabeth Castillo, M.P.H., Alisa Hughley, Crystal Moffett, Tonia Tillery, and Rueben C. Warren, D.D.S, Dr.P.H.

INTRODUCTION

Despite significant echnological and medical advances in diagnosis and treatment, racial and ethnic disparities in health status and access to health care persistent as public health concerns. Differences in quality of health care received have been well documented, with the low income and black patients receiving worse care.
To properly identify and interpret the causes of these disparities, improvements in the reliability and cultural appropriateness of existing data collection instruments and assessment of the data collected must occur.

Concerted efforts have been made to over sample various minority population groups. Nevertheless, the needs of minorities and special populations remain inadequately assessed and integrated into data collection efforts. The theme of the 1995 Public Health Conference on Records and Statistics and the National Committee on Vital and Health Statistics 45th Anniversary Symposium, convened by the National Center for Health Statistics (NCHS) was "Data Needs in an Era of Health Reform." The purpose of this paper is to discuss approaches and methodologies for improving the collection and analyses of data on the health of minorities and other special populations.

BACKGROUNG

The Report of the Secretary's Task Force on Black and Minority Health, released in 1985 is the most significant official Federal publication which documents disparities in health status and access to adequate health care among racial and ethnic populations in the United States. The Report served as the official impetus for research and public health policies to document, understand, and improve minority health in this Nation. Many of the determinants of the observed disparities identified then (e.g., SES, poverty, race, ethnicity, barriers to appropriate care, etc.) still remain national problems.

Efforts to systematically reform health care and public health nationwide, however, are not new. In 1974, President General Ford signed into law the National Health Planning and Development Act (P.L. 93-641), authorizing a three-year health planning and facilities program. Title XV of the Act established national, state, and local organizations for health planning and combined existing health planning programs. The second part of the Act, Title XVI, revised and extended the medical facilities construction (Hill-Burton) program and authorized funds for developing health resources nationwide. The 1994 Act established a network of regional Health Systems Agencies (HSAs) for areawide health planning and development in health services areas to be designated by State Governors.

In 1990, after three years of development and several public hearings, then Secretary of Health, Dr. Louis Sullivan, implemented a new national strategy for significantly improving the health of all Americans -- with particular focus on prevention. The document, entitled *Healthy People 2000: National Health Promotion and Disease Prevention Objectives, contained over 400 health-related objectives* grouped into 22 priority areas to be achieved by or before the Year 2000. Ambitious as many of the objectives are, approximately 100 new subobjectives and data sources for minority populations were added in 1994 in response to a midcourse reviews of the original objectives.

Also in 1990, the U.S. Congress passed the *Disadvantaged Minority Health Improvement Act of 1990.* The Act provides national guidelines and laws for health services programs, research and data collection and analysis aimed to reduce and alleviate the disproportionate burden of illness, disabilities, and deaths borne by racial and ethnic minority populations int the United States. The Act aimed also to institute Federal, State, and community-based health programs for removing socioeconomic, linguistic, and cultural barriers to appropriate health care for member of the various minority population groups. The Americans with Disability Act of 1990 seeks also to do the same for the over 20 million Americans with various types and degrees of disabling (health) conditions.

The current debate in this health care reform era is, largely about approaches for ensuring access to adequate health care, at a reasonable cost, for everyone in the US without compromising quality. The concern is especially for low-income and medically indigent persons who are traditionally underserved or left out of the existing predominant fee-for-service health care system. The focus of this 1995 NCHS- sponsored conference appropriately must address records and statistics needed for health reform relative to emerging public health issues. To be most relevant to the current National debate the conference must highlight the critical and growing role of data in the changing health care system.

ASSESSING THE HEALTH OF SPECIAL POPULATIONS

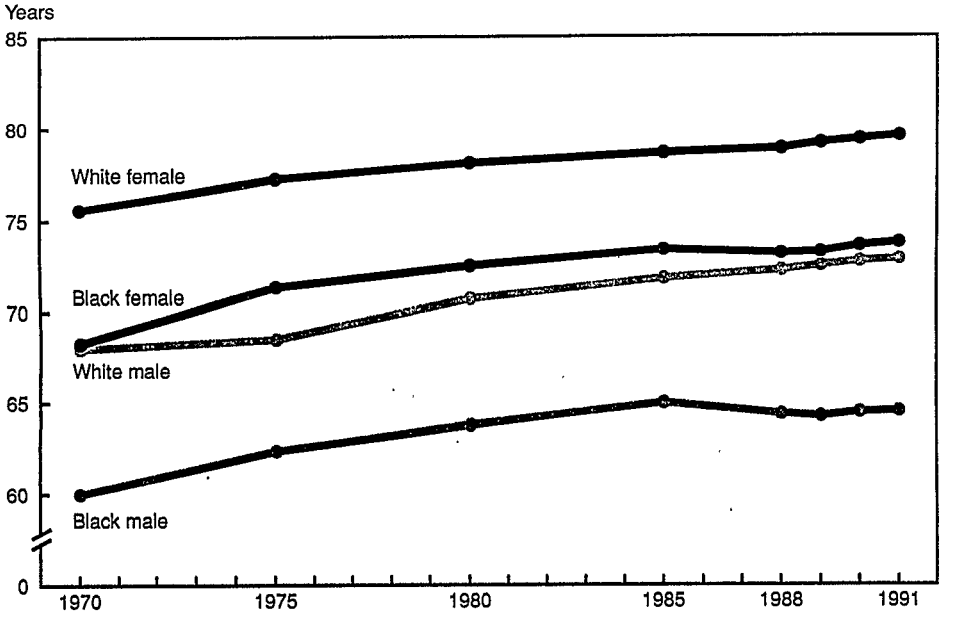
Health needs assessment requires succinct definition of a desired state (target) of "health" and an accurate knowledge of the present (baseline health profile of the community or individual. Data from existing national data collection systems maintained by NCHS and other federal agencies were used in establishing the baseline, and indeed most of the Year 2000 health status targets for the various subpopulation groups. Some of the national population-based and vital statistics data collection systems can be used to get a general idea of the health status of Americans. However, these data are neither adequate nor appropriate for assessing the health needs of minorities and other special populations at State and local (community) levels.

The three major goals of "Healthy People 2000" are to (1) increase the span of healthy life for Americans; (2) reduce health disparities among Americans; and, (3) achieve access to preventive services for all Americans. A special category of seven objectives were established to improve public health surveillance and data systems by the year 2000. Compared to their white counterparts, blacks in America have always had shorter life expectancy which has been consistently 5 to 8 years shorter than whites in the last two decades, 1970-1990. The life expectancy at birth for blacks in 1990 (69.1 years of life) is 7 years less than that of whites (76.1 years), and approximates where white Americans were forty years ago--- life expectancy of whites birth was 69.1 in 1950. In 1990 Black females could expect to live approximately 9 years longer than black males born the same year; but 6 years shorter than their white counterparts on the average. (Health, USA, 1993). For American aged 74 years and younger in 1993, the age-adjusted death rate for blacks was 615 per 100,000 population compared with 352 per 100,000 population for white Americans.

Twice as many black babies do not live to their first birthdays, compared to their white counterparts. The infant mortality rates for blacks have been at least twice that of whites during 1970 through 1990; 32.6 and 18.0 deaths per 1,000 live births for blacks compared with 17.8 and 7.6 deaths per 1,000 live births for whites in 1970 and 1990, respectively. (NCHS, Health USA, 1994). In terms of access to and utilization of appropriate health care services, fewer pregnant black women receive or initiate prenatal care during the first trimester of their pregnancies compared with their white counterparts (NCHS,Health USA, 1994). Compared to whites, a higher percentage of blacks, Hispanics, and low-income Americans lack a regular source of primary health care. (NCHS, NHIS, 1992).

Mid-course reviews conducted by the NCHS and the US Public Health Services to review progress toward achieving the Year 2000 objectives (NCHS, 1994) and statistical projections based on 1990-1993 data predict that all minority population groups will not only miss several of their Year 2000 objectives, but will actually be worse off in year 2000

Figure 1. Life expectancy at birth by race and sex: United States, 1970–91



Race and sex	1970	1975	1980	1985	1988	1989	1990	1991
White male	68.0	69.5	70.7	71.8	72.2	72.5	72.7	72.9
Black male.....	60.0	62.4	63.8	65.0	64.4	64.3	64.5	64.6
White female	75.6	77.3	78.1	78.7	78.9	79.2	79.4	79.6
Black female	68.3	71.3	72.5	73.4	73.2	73.3	73.6	73.8

SOURCE: Centers for Disease Control and Prevention, National Center for Health Statistics, National Vital Statistics System. See related *Health, United States, 1993*, table 27.

than their health profiles indicate they are in 1995. For example, objective 14.1 of "*Healthy People 2000*" is to reduce infant mortality rate to no more than 7 per 1000 live births for all Americans by Year 2000 (from a baseline of 10.1 per 1000 live birth in 1997),and to reduce the black infant mortality rate to no more than 11 per 1000 live births (from a baseline of 17.9 per 1000 live births in 1987).

Regression analysis of 1970-81 and 1981-88 data, however, project within 95 percent confidence interval that both targets for infant mortality rates will be missed, given current statistical pattern. The gap in infant mortality rates between white and black Americans will actually widen by Year 2000 if the current trend continues. (Feinleib, 1993).

Assessing the health needs of minorities and other special population is methodologically complex and difficult. But, it must be done well. Policy and program discussion must be based on accurate and reliable data if appropriate health programs are to be instituted to reduce the disparities in health status among Americans. The challenge for health planners and public health practitioners in general is the fact that Year 2000 is only five years away and much remains to be done.

Much of the debate about health care reform concern medical care services, albeit at the expense of public health services. A national objective (#22.4) for Year 2000, however, is the development and implementation of a national process to identify significant gaps in the national disease prevention and health promotion data, including data for racial and ethnic minorities, people with low income, and people with disabilities. Mechanisms must then be established to meet these needs. (HP 2000 objectives, U.S. - PHS). Disease prevention and health promotion data in this context include data on various disease status, risk factors, and health care services received. Public health

problems include issue areas such as HIV infection, domestic violence, mental health, environmental health, occupational health, and disabling conditions.

Comprehensive assessment of the health needs of minorities and other special populations require that specific standardized data elements be routinely collected in all the areas previously listed. The data elements must be integrated into standardized data sets. The office of the Associate Director for Minority Health, Centers for Disease Control and Prevention (CDC), in collaboration with the PHS-Office of Minority Health (PHS-OMH), the NCHS, and the Regional Minority Health Research Center at Morehouse School of Medicine are engaged in an on-going project known as the "*A Critical Review of Status and Trends in the Health and Quality of Life of Racial and Ethnic Minority Population in the U.S.*". Initiated in 1991, the project seeks to update the status of minority health in, the U.S. since that release of the 1985 Report of the Secretary's Task Force on the Health of Blacks and other minority populations. The project uses, and will enhance, existing surveillance systems to monitor progress toward the Year 2000 objectives and beyond for racial and ethnic minority populations. An aim of the "Critical Review Project" is to develop a systematic method for assessing the adequacy of existing data systems for monitoring minority health status and quality of life indicators. In 1994, an update of excess deaths among blacks and Hispanic was published by NCHS. Under the supervision of the Senior Epidemiologist for Minority Health, research assistants at the Morehouse School of Medicine's Regional Minority Health Research Center developed a stepwise approach in Component II of this initiative to assess the adequacy of existing data systems for minority morbidity and disability among the various racial and ethnic minority population group. The steps include:

Step 1. Complied Diseases and Health condition - specific measures and Indicators (HP 2000 objective and Critical review Project;
Step 2. Compiled Statistical Variable/Data Elements needed to compute the Measures/Health Indicators (above);
Step 3. Identified Sources of Data (Data Systems) containing the data elements, (published and electronic sources);
Step 4. Developed Criteria for assessing the adequacy of existing data systems for computing specific measures of health status;
Step 5. Reviewed documentation/ detailed descriptions for various data systems;
Step 6. Identified Gaps/ Inadequacies in existing data systems;
Step 7. Developed Recommendations for filling the gags.

Disease-and health condition-specific measures and indicators were compiled for HIV/AIDS, the six diseases and health conditions highlighted in the 1985 report (cardiovascular diseases and stroke, cancer, homicide, infant mortality), and the cross-cutting issues (access to and financing of health care, and health professions).

SOURCES OF DATA FOR SELECTED HEALTH STATUS INDICATORS

STATISTICAL MEASURES	STATISTICAL VARIABLES	PROPOSED DATA SOURCES
Survival rates for all major cancers affecting minorities	SES Smoker/ nonsmoker Sex Age Demographic area Ethnicity	SEER NAMCS NHIS BRFSS
Prevalence of tobacco use	SES Sex Age Demographic area Incidence of lung cancer Ethnicity	SEER NHIS NHANES BRFSS HHANES YRBS
Prevalence of IV drug use	SES sex ethnicity demographic area drug abuse and type	NHSDA DAWN MFS HIV Sero in Drug Treatment Centers
Prvalence of HIV infection	SES sex ethnicity demographic area	NHIS NHDS NHANES AIDS Surveillance HIV Counseling and Testing
Prevalence of condom use in the sexually active	SES sex ethnicity demographic area knowledge /attitude about AIDS sexual practices/attitude	NHIS NSFG
Minorities reporting environmental or chemical exposures at work or home	SES Sex Age Demographic area Smoker/nonsmoker Incidence of lung cancer Type of exposures Ethnicity	SEER NHIS NHANES NOES HHANES NHDS NOHS OED
Long term disability (mental or physical)	SES Sex Ethnicity Demographic area	NHIS NHANES I NNHS NHHCS LSOA
Impact on Family and Significant Others	SES Sex Ethnicity Demographic area Stress Depression Days lost from work/school	NHANES NHIS
Implications for Employment	SES Sex Ethnicity Demographic area Depression Loss of Job	NHANES NHIS

More importantly, a set of criteria was developed for assessing the adequacy/ utility of existing data systems for use in computing the specific health status indicators. Adequacy of a data system for minority health depends mainly on the variables and data elements in the data system, as well as the size and ethnic/national (origin) diversity of minority populations included.

Selected criteria for assessing adequacy of existing data systems for minority health

1. Whether the data system contains variables (data elements) for health measures of interest;
2. Whether incidence and prevalence rates are attainable;
3. Appropriateness of sampling frame,
4. At the minimum, contains racial and ethnic classifications as defined by OMB Directive 15;
5. Number of minorities in survey samples, whether oversampled minority population groups;
6. Periodicity of data collection; and,
7. Availability of comparable denominator.

Information needed for comprehensive assessment of the health needs of a community should include:

1. Geographic (Regional) Information

PHS Region
State
County
SMSA
City - Zip Code
- Census Tract
- Street Name
- Household Address

2. Demographic Information

Age, Gender
Race
Ethnicity/National Origin
(i.e.,Cultural Background)
Native born/Foreign born
Generation represented in the U.S.
Duration of Residency
-in the geographic region
-in the U.S. (if "foreign born")
Marital Status
Socio-economics
-year of schooling completed
-type(s) of employment, etc. (if employed)
-monthly and annual income (net income)

Detailed Household Information
-number of persons in the household
-head-of-household
-name, age, gender of persons in the household
-literacy in native language
-literacy in English

3. Health Status Indicators (partial List)

-Prevalence of Coronary Artery Disease
-Numbers of ER Visits for Angina and Chest Pain
-Prevalence of Hypercholesterolemia (>or=240 mg/dl)
-Prevalence of Obesity (m>or=27.8; f>or=27.3)
-Prevalence of Diabetes Mellitus
-Proportion of Regular, Moderate, or Light Exercise
-Number of children ≤2 years immunized
-Impact of Family and Significant Others
-Implications for Employment
-Prevalence of Hypertension
-Health care expenditure for rehabilitation services for post-stroke victims
-Long term disability (mental or physical)

4. Community Resources/Structure

A. Administrative
-local political structure
B. Programmatic
Resources facilities and Personnel)
-Social Services, Personnel and Facilities
-Health Services,Personnel, and Facilities
(Types of services available, number of beds, proprietorship, number & types of personnel, #MDs/other providers accepting medical/medicare, etc.,)
-Educational Services, Personnel and Facilities
-Public Services/Safety, Personnel and Facilities

5. Environmental Information (at Census Tract/Zip Code level)

-Types of Business;
-Size of Company (No., race, age, gender, and national origin of employees;)
-Industries (types, types of products, types/ levels of emissions)
-Types of pollutants and pollution levels (daily/monthly average)
-Water Supply System (Sources)
-Landfills (location and type).

LIMITATIONS OF EXISTING DATA SYSTEMS FOR ASSESSING MINORITY HEALTH NEEDS

Existing (national) population-based data systems are neither adequate nor appropriate for assessing health needs of minority and other special populations. Based on an application of the selected criteria (Fig. 1) to mostly used cited existing sources of minority of minority health data, the following limitations were identified:

- Inadequate/small numbers in survey sample, unstable estimates;
- Underreporting of race (e.g. NHDS);
- Inappropriate Sampling frames, lack of appropriate denominator;
- Lack of data elements for assessing nativity, period of immigration, and generation in the U.S.;
- Inadequate data elements for Socioecomic Status;
- Lack of longitudinal data for planning and needs assessment;
- Varied/Incomplete collection of race/ethnicity data at some State level.

Much of the data elements required for a comprehensive assessment of the health needs of minorities and other special populations are either not being collected at all by existing data systems, some are being collected though by methodologically incompatible surveys, or suffer from lack of detailed information on representative number of minority populations in their samples.

PROPOSED SOLUTIONS AND APPROACHES FOR IMPROVING ASSESSMENT OF MINORITY HEALTH NEEDS

A specific national objective (#22.3) for year 2000 is to develop and disseminate among Federal, State, and local agencies procedures for collecting comparable data and to incorporate these procedures into Public Health Services (PHS) data collection systems. The development and dissemination of such comparable procedures for data collection would facilitate comparability of data on health status within and among State and local areas and would permit the valid comparison of local and State health data with national data. (DHHS,HP 2000, 1991).

The following are some recommendations for designing studies and appropriate procedures for collecting data to assess the health needs of minorities and other special populations. In all instances, the purpose(s) of the data collection should be stated clearly and communicated to the community/ populations of interest.

Study Design(s) and Data Collection

Data element collected and sampling frames used by existing data collection mechanisms often fail to give reliable representation of cultural diversity. Current survey use OMB directive 15's definitions of racial and ethnic populations in the U.S. However, obtaining specific information about national origin rather than using an ethnic or racial approximations would be more informative. This type of data yield useful information especially when it is considered along with recency of immigration or length of residency. Surveys that inquire about health care utilization should include more minority physicians in private practice and traditional (community) healers in their sample because these are often used by special populations.

Study design should:

- Depend on the purpose of the study health issue, and population of interest;
- Establish mechanisms and systems for longitudinal data;
- Use appropriate standard populations;
- Oversample more subgroups within subpopulations;
- Involve minority populations in <u>all</u> phases of the project;
- Relate data elements to core health indicators/measures.

Data collection should:

- Expand beyond minimal classification in OMB Directive 15;
- Develop uniform core questions for all new data collections;
- Establish procedures for longitudinal data collection;
- Face-to-face <u>vs</u> telephone household survey;
- Plan comprehensive periodic survey focusing on minority population (regional/ community based);
- Establish panel of experts for kinds of data needed;
- Ascertain language competence of target population;
- Use and involve neighborhood (community) health centers;
- Employ indigenous outreach workers.

Data Analyses

Several published sources that analyze available data do not analyze the data such that it can be used for accurate assessment of the health of special population. For example, there must be rationale behind age groupings.

Data analyses should:

- Provide rationale for the use of race and ethnicity/national origin;
- Establish similarities before grouping;
- Provide rationale for age groupings (i.e., stages of human development, etc.);
- Go beyond descriptive analysis to more multivariate crosstabulations and regression analysis;
- Perform more intra-group analysis (inter-group comparison is still needed);
- More categorical data analysis; and
- Identify "models" of effective intervention(regional and local variations).

DISCUSSION

Much has been said and written about "enrollment form" and "encounter form" in the context of health care reform. However, the proportion of short-stay hospitals not reporting race in National Hospital Discharge Survey (NHDS) is increasing with increasing use of automated data collection systems. More reliable data are needed than medical care data for comprehensive assessment of the health needs of minorities and other special populations. Standardized set of data elements and health status indicators should provide information about community health, personal health, environmental and occupational health, as well as mental health needs of the community. The concept of "community diagnosis" as compared to "personal diagnosis" should be employed in any comprehensive assessment of the health needs of minority populations.

Health needs assessment per se is useless without the use of the information to plan, implement, and evaluate appropriate health programs needed. Data collection systems and agencies should be encouraged to go beyond the minimal race and ethnicity categories in OMB Directive 15. In addition to Hispanics, Asians, and Pacific Islanders, the heterogeneity and increasing cultural diversity of blacks in the U.S. needs also be reflected in future data collection systems.

Reliable baseline assessment is crucial for health planning and evaluation. Expanded State-based utilization of standardized health status indicators and comparable procedures for data collection will enhance the appropriateness and utility of data systems for assessing the health needs of minorities and other special populations beyond year 2000.(DHHS, NCVHS 1993 Annual Report).

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EXPLORING THE DATA ON AFRICAN-AMERICANS AND OTHER MINORITIES AVAILABLE IN AUTOMATED AMBULATORY MEDICAL RECORD SYSTEMS

Harvey Schwartz, Agency for Health Care Policy and Research
Rene Kozloff, Selma Kunitz, James Campbell, and Ed Hammond

INTRODUCTION

Patient care quality, costs, outcome, and access are primary issues facing today's health care industry, its reimbursers, and consumers. Currently, limitations of existing patient care data hamper the ability of researchers and clinicians to assess the differences in the way health care is accessed by and delivered to different populations and the impact of these differences on the outcomes from care. The study described in this paper identified extant Automated Medical Record Systems (AAMRS) containing health-related minority data. The study explored whether these data could be aggregated to address the following research question: Are there racial/ethnic differences in the treatment and outcome for patients with hypertension? In phase I of the study records were identified and obtained from AAMRS to describe the value and quality of the data to be pooled across data sets to address the question. In phase II analytic approaches to these data sets were explored, described, and tested.

PHASE I METHODS

A review of potential AAMRS was conducted. Seven data base owners were identified and sent a solicitation letter and short questionnaire which queried the relevance of the data in their data bases to the research question to be answered. Of these seven owners, only two were able to comply with the request, furnishing data, on diskette, within the time frame necessary.

Fulfilling the request was difficult for data base owners and data management staff because of the time required and the logistical problems involved, and the financial and time costs of data retrieval. In addition, technical constraints impeded acquisition of data. Many of the data are stored in data bases designed for clinical care in ambulatory settings; to meet the research needs of this project, a great deal of programming and effort was required to make the data suitable.

DATA SET EXPLORATION

Data sets from University of Nebraska Medical Center (UNMC) and Duke Medical Center (Duke) ambulatory settings were selected for the project. After controlling for number of visits (> one), age (45-75 years), and primary diagnosis (hypertension, ICD-9 code 401-404), 1468 patient records from the UNMC data sets were eligible and 958 from Duke were eligible. Scrambled identifiers were used on all records to protect the privacy and confidentiality of the patients.

Race/Ethnicity Data

Race/ethnicity descriptors were collected and stored in both data sets. The number of minorities, other than blacks, represented in both data sets were small. (Table 1) OMB's Directive 15, which sets forth race and ethnic standards for Federal Statistics, was used as a comparative base and its racial/ethnicity definitions were not altered. (Table 2) Although different codes were used by UNMC and Duke, they were matched and recoded. The Duke data set was missing a large number of racial/ethnic data and no materials were available to document how the data which were available were collected and by whom. No distinction was made between missing and unknown values. In addition, in the UNMC data set, all data coded for ethnicity were missing, but some ethnicity data were found in "race."

Other Demographic Data

Education, occupation, and socioeconomic data are often used to complement race/ethnicity data in analysis. These data as well as gender, age, and marital status influence the use of health care services, barriers to health care, and treatment outcomes. As important as these data are believed to be, they were often missing or incomplete in not only the UNMC and Duke data sets, but also in the other data sets which were reviewed. For example, only Duke collects data on education and even these are fragmentary (58% of the values were missing). UNMC does not store occupational data and the data collected by Duke determine only whether or not the person has an occupation. Gender data were available on all patients in both data sets. Age was also available in both sets and was either collected at the time of visit or calculated from the date

of birth. Marital status was available for almost all patients in each data set.

Medical History, Encounter Related, Laboratory Measures, and Treatments

Medical history, encounter, laboratory and treatment regimen influence the relationship between race/ethnicity and the treatment of and outcome from disease. Like demographic data, many of these variables were not available in the data sets reviewed. Age at onset was found in only the Duke data set, but comorbid diseases and smoking/alcohol use were found in both. Several comorbid diseases are applicable to hypertension and both UNMC and Duke use ICD-9-CM codes to record them, although Duke will sometimes use a (TMR) code specific to their text. The parameters for smoking and alchohol were not clearly defined, were recorded unevenly in each data set, and were often missing. Level of exercise was collected by UNMC, but not by Duke; family history of hypertension was unavailable in the UNMC data set and not typically used in the Duke data set. Encounter-related data and laboratory measures were contained in both data sets. Encounter data varied slightly between UNMC and Duke while laboratory measurements appeared to be collected in the same format. Data on treatments, (pharmaceutical therapies and behavioral interventions), were collected unevenly. For this reason, a subset of medication was selected for analysis.

DATA QUALITY AND COMPARABILITY

The quality and useability of any data contained within a medical record or a data set is influenced by the many steps of the data collection process. Each physician-patient encounter generates data and creates the opportunity for error. Data reporting by the patient, data collection by the provider, data capture (whether automated or manual), data entry and data retrieval influence the quality of the data. Assumptions about the data are often made away from the physician-patient encounter. These are often not documented and influence the data. For example, both UNMC and Duke data sets contain a number of "blanks" and available documentation does not indicate whether these are missing data or unknowns. It is also unclear, especially in reference to race and ethnicity categories and quality of life data, how determinations and classifications are made. Individual interpretation and provider/collector idiosyncracies will thus influence the collection of many of these data.

Treatment outcome and quality of life are difficult to assess across data sets. Data elements and collection procedures are not standardized and do not lend themselves to reprogramming to increase uniformity. As is seen in UNMC and Duke data sets, and others reviewed, the process of care is not detailed and data from any care received in a secondary setting or in anecdotal episodes are not collected.

The UNMC and Duke data sets were often incomplete. Lack of standardization, irregularity of collection, or simply data not being collected, all influenced the comparability of the data sets and the ability to link them to answer the medical effectiveness question.

VALUE OF THE LINKED DATA

Despite the fact that the data were not collected for these purposes -- to link across data sets and for medical effectiveness research, data from the two data sets were "linkable" in the sense that data collected in disparate health settings could be aggregated at a level which allowed effective medical effectiveness research. This finding is important to future research. Data pooled in this method allow a variety of data elements and fields to be compared and draw from a larger population than is available through a single institution's records. By addressing the data deficiencies noted in this paper, these could become excellent sources of research data.

PHASE II METHODS

Patients, aged 45-75 years, with a diagnosis of hypertension were extracted from the Duke and UNMC data sets and divided according to OMB's Directive 15 into two racial/ethnic groups -- "white" and "other races." (Table 3) Outcome variables were chosen and predictor or antecedent variables were defined. Data sets were recoded and structured to allow the data sets to be analyzed.

FINDINGS

The reporting of race and ethnicity reflect differences between the Duke and UNMC data sets. The UNMC data set contains race/ethnicity for almost all of the patients; however, 48% of the race/ethnicity data is missing in the Duke data set. These records could not be included in the main analysis. In order to assess the generalizability of the findings for the remaining patients, a series of chi-squares was used to evaluate differences in outcome variables or explanatory variables between the

group with missing race data and the 52% of Duke's patient records remaining for the main analysis. Table 4 shows the findings. The patients with missing race/ethnicity data do not differ significantly from the remaining group on gender distribution, myocardial infarction after first visit, or whether antihypertensive medications were ever used. However, there is a significant difference ($p<.013$) in the proportion of patients hypertensive at the end of the study; 44% (n=204) of patients with missing race data were hypertensive while 36% (n=181) of those with complete race data were hypertensive. There is also a marginally significant difference ($p<.085$) in the proportion of patients having a stroke after first visit; 3% (n=14) of patients with missing data had a stroke after first visit while 1% (n=7) of those with complete race data had a stroke after first visit.

While there is a significant difference (t-test with $p<.001$) in the mean ages (approximately three years) of the patients, the clinical significance of the difference is unclear. Non-significant differences in gender, stroke or myocardial infarction after first visit, and use of antihypertensive medication may be clinically significant, but it is not possible to determine if they are race/ethnic related.

In comparing the Duke and UNMC populations, we found that there is no difference in the age or gender of the two samples, but there are differences in all other demographic and outcome variables. The patients at UNMC were predominantly "white" while at Duke, they were evenly divided between "white" and "other races." However, the Duke data reflect only those patients for whom there is racial/ethnic data.

The relationship of race/ethnicity to outcome was explored using a logistic regression model. Table 5 shows the findings. Race did not influence the occurrence of stroke after first visit or myocardial infarction after first visit. Moreover, when the occurrence of either stroke or MI after first visit were evaluated together, race/ethnicity was the only predictor shown to have a non-significant effect. The presence of hypertension at the end of the study was not shown to be influenced by race/ethnicity.

DISCUSSION

Because racial/ethnic data were missing from 48% of the Duke data set, this key variable could not be analyzed for the total data set. Therefore, those patients with racial/ethnic identifiers and those without these identifiers were compared. Results indicate that these two groups do not differ on gender, proportion with a myocardial infarction, or use of antihypertensive medications. Analyses of other variables, such as obesity or the use of specific antihypertensive medications were considered. However, because of the paucity of data and/or the absence of racial categories, the analyses would not have been meaningful. While the mean ages of the patients in the two groups were statistically different, the 3 year average age difference does not seem meaningful from a clinical standpoint. Duke patients with missing race data were more likely ($p<.013$) than those with complete racial/ethnic data to be hypertensive at the end of the study. (Table 4) Duke patients with missing race data were also marginally more likely ($p<.085$) than those with complete racial/ethnic data to have had a stroke after the first visit. (Table 4)

The literature suggests that there is often misclassification of racial/ethnic minorities but the bias that the misclassification introduces in understanding differences in diagnosis, treatment, and outcomes is likely to be negligible. Blustein found that admitting clerks were most likely to obtain and record this information.[1] A careful review of biomedical, epidemiological, and research data suggests that missing racial/ethnic data cannot be determined nor is there an *a priori* method for imputing the information. The Census Bureau imputes missing race/ethnicity data from other family members, housemates, neighbors and the neighborhood in general.[2] This approach is not generally applicable in the case of medical records where the individual generally presents alone and the race/ethnicity of next of kin is not recorded.

Little is known about patterns of missing race and ethnicity data in patients' medical records and it is unclear whether the provider gathering the data, the setting in which the data are gathered, or the actual race and ethnicity influence the proportion of missing data in these categories. We recommend that this issue be systematically studied.

Some research suggests that the health seeking behavior of minorities, because of their lower socioeconomic status, lack of access to care, or fear of the health care system results in their receiving care later in the disease process and with less regularity than non-minorities.[3] It is possible that their first encounter with the health

care system is on an emergency basis, where obtaining demographic information is not the first concern. Further research into the distribution of those whose race/ethnicity is classified and those for whom it is not would shed light on the meaning of this missing data.

In order to address the racial/ethnic question posed for this study, comparison across the Duke and UNMC data sets included only those Duke patients (n=497) whose race/ethnicity was recorded on the patient record. The elimination of patients without racial/ethnic identifiers hinders the generalizability of the findings; however, it did enable analysis of the data.

Patients at UNMC who had race data were predominantly "white", while at Duke, they were evenly divided between "white" and "other races." It appears that UNMC patients were "sicker" at the end of the study; that is, were more likely to have myocardial infarction or stroke, and more likely to be hypertensive at the end of the study. This may reflect patient status or, in fact, more complete record keeping on a population who regularly seeks care at the same facility. It is interesting to note that this population at UNMC is more likely to have been prescribed antihypertensive medication.

The contribution of individual predictors to the outcome from treatment was assessed. Stroke after first visit and hypertensive at end of study were associated with site, as described above. Stroke was more likely to occur in patients who used antihypertensive medications. Because stroke is often associated with continued elevated blood pressure, it is not surprising that these two associations occur together. Perhaps, it is the "sickest" patients, the ones with most complications, who receive medication and therefore, antihypertensive use is also associated with site. Myocardial infarction after first visit was associated with antihypertensive medication use, and also with site and gender. When combined, that is, stroke *or* myocardial infarction after first visit, all predictors except race were significant. Moreover, the significance of race/ethnicity does not appear to be meaningful (22.7% whites vs. 21.7% blacks) in the combined analyses, and does not play a significant part in predicting either event separately.

Reasons for these differences are not clear. The literature suggests that black patients, who in this study represent the majority of the "other races" population, are likely to be sicker and less compliant than white patients.[4] While UNMC appears to have a greater proportion of white patients who are "sicker", much of the racial/ethnic data (48%) is missing from the Duke data set and comparisons cannot reasonably be made. Differences in collection, entry, and retrieval of data may also contribute to the difference. Or in fact, patients at UNMC may be sicker when they present for treatment. Duke may follow patients more aggressively and make more referrals for behavior modification of risk factors, thereby using fewer medications and showing better outcomes from treatment. Because these data were not available in the data sets, no definitive evaluation can be made.

CONCLUSIONS AND RECOMMENDATIONS

Because of the differences in racial distribution and the dissimilarities of the sample population in the two data sets, only a portion of the data could reasonably be pooled to address a medical effectiveness research question.

Little is known about the meaning of missing racial/ethnic data. It is unclear whether it reflects minority status or is influenced by the provider collecting the data or the setting in which the data are gathered. Training of providers for systematic racial/ethnic data collection may result in more reliable data.

Further research is needed to assess the role of race/ethnicity in the identification, treatment, and outcome from hypertension. Efforts must be made to understand and document the way in which racial/ethnic data are collected, by whom, and with what assumptions. The meaning of missing racial/ethnic data must be explored. Based on the characteristics of the data sets explored in this study, we would not *a priori* recommend aggregating data across care centers. As shown, each of the potential data sets must be explored and defined and the differences assessed with respect to the research questions posed. If researchers can use AAMRS care data to perform medical effectiveness research, they must be cognizant of its limitations in both content and quality and incorporate these limitations into their findings.

TABLE 1: RACE/ETHNICITY OVER POOLED DATA (OMB DIRECTIVE 15)

	Blank	Am Ind Alaskan	Asian/ Pac Is	Af Am/ Black	Cauc/ White	Hispanic	Total
DMC	461	1	5	237	253	1	958
NMC	10	11	12	363	1062	10	1468
Total	471	12	17	600	1315	11	2426

Note: DMC = Duke University Medical Center; NMC = Nebraska University Medical Center.

TABLE 2: OMB DIRECTIVE 15 RACE/ETHNICITY CATEGORIES

American Indian or Alaskan Native
Asian/Pacific Islander
African American/Black
Caucasian/White
Hispanic--1 ethnic group

TABLE 3: RACE/ETHNICITY OVER POOLED DATA (OMB DIRECTIVE 15 "REDUCED FORM")

	Blank	Cauc/ White	Other Races	Total
DMC	461	253	244	958
NMC	10	1062	396	1468
Total	471	1315	640	2426

TABLE 4: DUKE - PRESENCE OF RACIAL/ETHNIC DESCRIPTORS *

	No R/E Data		R/E Data		χ^2	p value
	N	%	N	%		
Hypertensive at End of Study					6.105	0.013
No	257	56%	316	64%		
Yes	204	44%	181	36%		
Stroke after 1st Visit					2.958	0.085
No	447	97%	490	99%		
Yes	14	3%	7	1%		

* only significant and marginally significant results are shown due to space limitations

TABLE 5: OUTCOME AFTER FIRST VISIT OR AT END OF STUDY *

Predictor	**A ** p value**	**B ** p value**	**C ** p value**	**D ** p value**
Site	0.001	0.000	0.000	0.000
Gender	NS	0.016	0.004	NS
Race/ Ethnicity	NS	NS	NC	NS
Antihy. Medication	0.000	0.000	0.000	0.003

* only significance of results reported due to space limitations
** A = Stroke after first visit; B = MI after first visit;
C = Stroke or MI after first visit; D = Hypertensive at end of study

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CULTURAL APPROPRIATENESS OF FOCUS GROUP METHODS: REPORT OF AN EXPERT PANEL

Rena J. Pasick, Northern California Cancer Center
Carol N. D'Onofrio, Larry Bye, Quita Bingham, Mary Lou Munguia

Introduction

Focus group research has become a widely accepted in and often integral to many types of public health inquiry. These range from the formative phases of health promotion research to testing educational messages and materials (Ramirez, 1988; Basch, 1987), and the development of health survey questions (O'Brien, 1993). In the course of our research on the cross-cultural comparability of survey methods and findings[1], we discovered a surprising void in the literature regarding the appropriateness of focus group methods across cultures.

Focus groups are small group discussion sessions among members of a study or program target population. Participants are guided through a standardized series of open-ended questions by a trained moderator to elicit individual responses. In this way, concepts can be generated, hypotheses explored, and idiomatic expressions identified. Over the past decade, a considerable body of literature has been produced, yielding generally accepted, standardized focus group procedures (Krueger, 1994; Goldman and McDonald, 1987). The ubiquitous use of this qualitative tool has elevated the importance of focus group methods and findings in public health policy and programs. Thus, the lack of thoughtful reflection on the cultural appropriateness of focus groups and their methodologic components has far-reaching implications. As a first step toward addressing this problem, we convened a panel discussion to explore the unique and important cultural issues that arise when conducting focus groups with specific race/ethnic groups.

Purpose and Approach

Our study of the comparability and validity of health survey methods and findings across race/ethnic groups, languages, and cultures included a series of focus groups in African American, Chinese, Hispanic, and Vietnamese communities. However, in planning these groups intended to explore the cross-cultural appropriateness of quantitative methods, we came to also question whether or not this qualitative approach can in fact be used in comparable ways across race/ethnic groups. A review of the literature revealed no prior consideration of this issue leaving us with the following questions. Are state of the art conventions in focus group methodology applicable uniformly across cultures and topics? Do researchers and moderators who conduct focus groups with members of their own race/ethnic group intuitively or explicitly adapt these methods to characteristics of the culture?

While many research reports briefly mention the use of focus groups with specific race/ethnic groups as a component of their study, comments are limited to the simple fact that groups were used, not how. In this information vacuum, myths, stereotypes, and hunches abound: "You can't do focus groups with Asians, because they are so reticent to speak among strangers;" and "you can't do them with American Indians because of distrust"; "focus groups on sensitive topics can't be done with Hispanics because there is a cultural reserve that would make this unthinkable;" and "the same group must be re-convened multiple times to elicit personal information from Filipinos, because they require an extended time period to establish trust." The first three comments mentioned above have been refuted through our own work and many other studies. The last is potentially valid, and is currently under investigation[2].

Because so much is being done with focus groups on different issues and with diverse populations, we believed that much could be learned about cultural appropriateness of the methods by mining the knowledge and experience of individuals who are skilled in the conventional methods, and who have conducted groups in their own race/ethnic community. For maximum dialogue, the format of a day-long panel discussion was chosen with two experts[3] from each of the four populations who are the focus of our current NCHS and other related studies (African American, Chinese, Hispanic and Vietnamese). The backgrounds of the panelists included public health and private sector market research.

Standard components of focus group research provided the framework for a moderated discussion consisting of panel dialogue and interaction with a multi-ethnic audience of about 30 of our research colleagues. Expert panelists were asked to provide culturally relevant examples and insights from their experiences related to: project design and planning (including definition of research questions and participant characteristics); specification of respondent recruitment methods; discussion guide development, through which the questions to be asked of the group are written and organized; definition of moderator characteristics and techniques; planning for the logistics of the group; and the analyses and interpretation of findings. The day concluded with summaries and responses from a multi-ethnic team of research assistants who had been trained to conduct groups and had

done so prior to the panel discussion.

Insights from the Panel

Project design and planning. Panelists were asked if there are certain topics that are best not explored using the group interview format. There were clear variations in the responses. For example, one of our Hispanic experts indicated that, once a person agrees to participate and actually shows up, they will be "open, and honored to speak". Any reticence would come up at the time of recruitment. However, our African American, Vietnamese, and Chinese panelists agreed that "self disclosure or disclosure about one's family is foreign;" that very sensitive topics might not be discussed openly until a great deal of trust-building occurred, and this probably could not happen in one session. This implies the need for a departure from the convention that focus group participants should not be known to one another, in order to permit greater openness. Instead the indication is that, for some cultures, participants may require greater familiarity to build trust with each other and the moderator.

This raises a question that was not resolved by the panel: If considerable time is needed to develop trust, would it be better initially to bring together people who are friends or family, or would that simply evoke a different set of problems? In fact, the Vietnamese and Hispanic panelists had very positive experiences with groups of people known to one another, and it was suggested that researchers convene both types of groups to assess the impact of familiarity.

The issue of trust was repeatedly raised during the panel discussion, particularly with regard to the importance of clearly stated purpose of the research. It was considered essential for the study team to be open and clear with the community about their reasons for conducting research. Also, it was said that participants should be informed of the ways in which their input would be used.

The composition of a focus group is another important design issue. Planners have been known to select participants based strictly on race or ethnicity, without consideration of cultural variability within groups. All of our panelists pointed out variations in their communities that could affect the dynamics of the group and the generalizability of findings. For example, for immigrant groups, there is heterogeneity due to acculturation such that persons from opposite ends of the acculturation spectrum may not relate well to one another. For all groups, educational, regional, gender, or even political differences can be important in this way, depending on the topic. Most of all, socio-economic differences figure prominently in all aspects of group design, implementation and interpretation.

Ultimately, all panelists agreed that the degree of segmentation (selection of homogeneous population sub-groups) or mixing of sub-groups depends very much on the topic of discussion. Several panelists mentioned that men and women should not be asked to discuss sensitive topics together; in general, it may be inadvisable to combine education or literacy levels; and generations should not be intermingled for discussion of certain topics such as sexual practices.

Recruitment. Recruitment of participants is central to WHO you get, and therefore WHAT you will get OUT of the group. How to recruit evoked some interesting differences. It was noted that low socio-economic status often negatively affects the ability of people to fulfill their commitment to attend a focus group, so more over-recruitment may be needed, ranging from 50% to two to three times the intended number. The convention for optimal size of a group is eight to 10 participants.

Method of recruitment also varied because of cultural differences. It was suggested that the best way to recruit Vietnamese respondents is through chain referral by people who know one another, to benefit from a community norm referred to by one panelist as "If you go, I go." Chain referral was also acceptable to Chinese and Hispanic panelists. Other methods suggested for African Americans and Vietnamese included the use of radio for credibility, and recruitment through trusted community-based organizations. The telephone was rejected as a recruitment method for Hispanics and Vietnamese, but considered acceptable for Chinese. Offering incentives in the form of payment was deemed desirable across all groups. Providing culturally appropriate food was emphasized as very important to comfort and rapport among respondents.

Discussion guide development. It is the convention to introduce the topic and participants as expediently as possible, explain that the purpose is to get their opinions, and then move to the substance of the discussion. For all the groups represented on our panel, this issue marked another departure from standard methodology. Trust-building was identified again as a significant agenda item that requires careful attention, planning and TIME. The description of the purpose is paramount because the entire concept of the focus group is unknown to most people.

It was also recommended that at least thirty minutes out of the usual one and one half to two hours is needed for socializing among Hispanics. One of the African American panelists said that the first two hours should be devoted to building trust, using the remaining third hour for the "real" issues. In fact, it was said that some of the

most important discussion occurs after the formal conclusion of the group, once the recording devices are turned off. At that point, people have become very comfortable and are speaking more openly and less self-consciously. This behavior, as well as many other characteristics of focus group dynamics, was evidenced by our own panel.

Some panelists expressed concern regarding the structure of focus group questions. It was reported, for example, that Vietnamese, Chinese, and African Americans are all "high context" cultures. This means that questions must be embedded in a meaningful context or storyline that people can relate to. Also, especially among African American and Chinese, non-verbal communication is very important. For all groups, the moderator must be able to interpret this and probe or respond appropriately.

Moderator characteristics. Some of the most lively discussion was generated by the topic of moderator characteristics and skills, particularly whether or not it is necessary to have an "ethnic match" between moderator and participants. All panelists agreed that the cultural competence of the moderator is paramount, and that a simple physical match is not sufficient. While they were not asked to derive a concise definition of cultural competence, the issues raised by panelists dealt with: the capability to generate trust and mutual respect through sensitivity to non-verbal cues; an understanding of the different culturally-influenced roles that participants might assume; and knowledge of how to properly respond. Good moderating skills are determined by the ability to moderate within a specific culture. The example was given of an African American group in which there may be a participant fulfilling the role of the "grio", the traditional story-teller. A culturally competent moderator would be able to acknowledge this role and incorporate it into the topic under discussion by making the relevant connections between the personal story and the discussion topic, without allowing the story to dominate or distract the group.

Vietnamese and Chinese panelists all agreed that an ethnic match was important for their communities, and that congruence in language was essential. However, it was mentioned that among Vietnamese, a young moderator might not be respected by either old or young participants. For the Hispanic and African American panelists, there was provisional acceptance of moderator diversity. For example, it was suggested that a skilled white moderator could function well with older African Americans, although this might not be the case with younger age groups. Our Hispanic panelists disagreed with one another on this matter. One panelist stated that, for older participants, the moderator should be Hispanic. The other panelist felt that a non-Hispanic moderator with good skills could be effective regardless of age group. For all groups, familiarity and facility with the vernacular was said to be very important.

It was suggested by one panelist that if you don't have enough moderators to match respondent culture and ethnicity, then you should "grow your own". This is what we did in our own study, by hiring and rigorously training a team of research assistants from the four ethnic groups previously mentioned.

Logistics. There was general agreement among panelists, regarding logistic arrangements for focus groups. The message conveyed was that it is best to go to the community, to familiar surroundings, for all of these populations. One Hispanic moderator indicated that the best group she ever conducted took place in a minister's living room with people who knew one another. This approach challenges the conventional practice, among those researchers who can afford to do so, of holding groups in professional facilities with hidden microphones and one-way mirrors. There were some culturally-specific logistical issues raised, including providing child-care for older African American women who may be responsible for their grandchildren; or holding groups during the day for Hispanic women, and at night for Hispanic men. Socio-economic differences affect these as well as other logistic issues.

Analyses and interpretation. On the subject of analyses and interpretation, there was general agreement that focus group findings and conclusions are highly subjective and thus readily influenced by one's "cultural lens". It was therefore recommended that multiple analysts review the data including those with diverse perspectives from within and outside the culture. Panelists cautioned against the over-generalization of findings to "all Hispanics", "all African Americans", "all Vietnamese" or "all Chinese" simply due to the race or ethnicity of participants.

Cross-Cutting Themes

Clearly, the impressions of eight individuals cannot be interpreted as valid or reliable principles. Like the findings generated through focus groups, the issues and conclusions raised in this gathering are not definitive or broadly generalizable. However, as is also true for focus group findings, the information gleaned is very meaningful as a basis for further research, and potentially indicative of real cross-cultural similarities or culturally-specific differences.

The dynamic, spirited, and thoughtful nature of this panel discussion is best conveyed through

the cross-cutting themes that emerged from the day. These themes address the issues of purpose, assumptions, heterogeneity and cultural competence in the context of focus group methodology. The most recurrent theme was emphasis on the importance of a *clearly-stated purpose* for focus groups, since this affects every element of the research, from recruitment methods and segmentation to moderator characteristics and the design of the focus group questions.

Panelists consistently warned of the hazards in erroneous *assumptions*, unidentified and unchallenged stereotypes, and over-generalization.

It was clear that our panelists were very sensitive to the implications of *heterogeneity*, particularly in socioeconomic status, in every aspect of focus group research. They also perceived a strong interaction between the purpose of research and the diversity within communities. Virtually everything about conducting the groups will be different with affluent, educated populations as compared with those who are poor and less educated.

Finally, all panelists agreed that the *cultural competence* of researchers and moderators is key to the validity of findings. This quality is not simply a matter of technique. Cultural competence demands sensitivity to and respect for the individual.

Preliminary Conclusions

From an overview of the entire day, we have drawn several preliminary conclusions. They are preliminary because, again, this was one day of discussion with eight professionals. Their insights are grounded in extensive experience, and as such can be viewed as sound hypotheses meriting further testing rather than definitive findings.

The panel's experience indicates that focus group research appears to be a valid and appropriate methodology in the four groups discussed. Some conventions such as the single session group may be inappropriate for some topics in some cultures; and some other conventions, such as the posing of questions in a discussion group format to elicit opinions, appear to apply across all these groups (although how questions are posed may vary). According to our panelists, cultural issues are particularly important in moderator selection and training, recruitment and segmentation of participants, and in facilitation techniques.

This focus group panel experience has generated a long list of unanswered questions that warrant further research. Some examples from the list include:

1. How does purpose affect segmentation and does this vary by culture?
2. How can diversity be represented?
3. What is the relevance of age/generation/gender differences in various race/ethnic groups?
4. Is discussion of sensitive topics culturally inappropriate for some groups?
5. What is optimal versus acceptable in moderator characteristics, and does this vary by culture?

The implications of research addressing these questions will be felt throughout public health and beyond, to other social sciences. This is merely the beginning of a needed dialogue and a call to research. We strongly encourage further investigations of the similarities and differences across cultures in focus group research.

Endnotes

1. *Improving Health Surveys for Multi-Ethnic Populations* is a grant to the Northern California Cancer Center (NCCC) from the National Center for Health Statistics (NCHS).
2. *Early Cancer Detection for Filipino Americans* is a grant to the NCCC from the Department of Defense.
3. We would like to acknowledge the panel participants: Marcia Canton, Lei Chun Fung, Nichelle Nickols, Bang Nguyen, Regina Otero-Sabogal, Amelie Ramirez, Chuoc VoTa, and Sandra Wong; Research Assistants: Maria Arrechiga, Quita Bingham, Jaclyn Chan, Thao Le, Ququan Liu, Mary Lou Munguia, Thiettranh Tran Pham, and Leah Vaughan; and Barbara Marin for her presentation.

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FILLING IN THE BLANKS: CREATING AND AGGREGATING SERVICE DRIVEN DATA TO DEVELOP COMMUNITY PROFILES OF SPECIAL POPULATIONS

Debbie Indyk, Dept. of Community Medicine, Mount Sinai Medical Center
Len Indyk

The confluence of poverty, AIDS, tuberculosis, substance abuse and violence in our inner city neighborhoods makes them key sites for reaching, assessing and developing approaches to prevention and early intervention among vulnerable and hard-to-reach special populations who are normally beyond the purview of the medical system until very late in the progression of the multiple diseases to which they are inequitably exposed.

The inner-city predominantly Latino and African American inner-city neighborhood, East Harlem, served by the designated AIDS Center of the Mount Sinai Medical Center, provided such a strategic setting in which to develop networks and nodes as loci for service delivery, prevention, education and research. The neighborhood encompasses a critical mass of individuals "exposed to" problems to be studied and a critical mass of "experts" who treat, study and experience the problem. The following two Tables of neighborhood demographics demonstrate the range of problems faced by the community and the severity of the impact of AIDS on the community.

TABLE 1 - SELECTED HEALTH STATISTICS NEIGHBORHOOD

No prenatal care	18%
Births-single women	73%
Births-women on medicaid	62%
Live births-teen mothers	15%
Low birth-weight deliveries	14%
Births-drug-using mothers	27%
Child abuse and neglect	13%
****	
Infant mortality	17/1,000
Tuberculosis	91/100,000
Cases-gonorrhea	430/100,000
Cases-syphilis	505/100,000

TABLE 2 - SELECTED AIDS STATISTICS NEIGHBORHOOD

Percent total NYC population	1.4%
Estimated total NYC HIV cases	13.5%
Deaths attributed to AIDS	11 %
Latino & African American	87 %
Percent total NYC pediatric AIDS	5 %
AIDS cases related to IDU	68 %
Estimated seroprevalence	12 %

The Aaron Diamond Foundation AIDS Prevention Project to the Department of Community Medicine provided the engine for sustained infrastructure building activities that fostered the development of such nodes. Table 3 shows the variety of settings in which the approach has been applied.

TABLE 3- TYPES OF SETTINGS

1. Family health service agency providing "one stop shopping"
2. Community health service for AIDS/HIV counselling
3. Street-based needle exchange program
4. Family-life program providing preventive services for high-risk families
5. Hospital-based AIDS Center providing inpatient & outpatient care
6. Directly observed therapy (D.O.T.) program for tuberculosis
7. Directly observed preventive therapy (D.O.P.T.) program for tuberculosis
8. Hospital-based employee health service.

The approach provides sustained support of resource program, staff and, most importantly, the capacity to organize, aggregate and analyze data to describe and assess the populations they serve and the work they do. As each agency elaborates its unique community based or family-centered care model and further develops its data-collection and analysis capabilities, the consultants help staff and administration move their work from case study analysis and observational studies to aggregate data-analysis.

The linchpin of the approach involved the implementation of a powerful, but easy to use PC-based MIS system which (1) permits agency-specific planning and evaluation of program activities, and (2) is critical as a first step in collecting and analyzing community-generated data.

Since the data collected are service-driven and include a great variety of non-reimbursable services, the needs and utilization profiles which we derive for these populations are quite different from those which can be obtained from the traditional sources, namely, hospital discharge data and medical insurance data.

The data-collection, analysis and reporting requirements of Community-Based Organizations and other types of stand-alone health-related facilities in the USA in the 1990's have become extremely complex. Most often, however, agencies develop systems which allow them only to collect those data required by their fundors. The various data systems are not linked and do not give the agencies the ability to fully describe who it is they're serving, for how long and with what outcome. The MIS system which we developed gives CBO's capability and flexibility which rivals that of a Medical Center's Data Processing department.

The methodology presented is applicable to a great variety of small organizations in many different types of practice settings. All of them currently face a similar set of requirements and challenges (Table 4).

TABLE 4 - 1995 - CHALLENGES TO A CBO

1. The continually changing needs of the community and agency
2. Limited resources which must be maximized in an economy of scarcity
3. Multiple funding streams with very different (but overlapping) reporting requirements
4. The impending and accelerated implementation of managed care
5. The reality that CBOs are often at the cutting edge of preventive, risk-reduction work but lack the resources to systematically assess and disseminate their work.

A typical full-service community-based family-centered organization delivers a variety of services to its clients. These services can be described in two separate, but overlapping groupings, Home based and Community based, as outlined in the next two Tables.

Typically, many of these programs are funded by different funding streams, with each funding agency requiring different reporting. Some of these programs request only headcounts of unduplicated services provided during a time period. A preventive program serving high-risk women might be required to describe the participation of these women in various programs. By integrating these various data-sets one is able to get a rich profile of the population (e.g mothers and their newborns, individuals and families) served by the agency, their needs, services provided and aspects of their health and socio-economic status. Furthermore, this information provides longitudinal data. Usually, little is known about these individuals until they enter the medical and social service system for emergent and reimbursable care.

In these agencies, even though their primary identity is as a "Family Health Service", the range of services utilized goes far beyond direct health

TABLE 5A - HOME BASED SERVICES

1. Community health nursing
2. Social work
3. Case management
4. Therapeutic counseling of families affected by HIV/AIDS
5. Pastoral care
6. Home health aide
7. Early childhood specialist
8. Parent/family aide services
9. Educational liaison to school.

TABLE 5B - COMMUNITY BASED SERVICES

1. Crisis walk-in service
2. HIV education/outreach
3. Legal services
4. Mothers' group teaching parenting and other life skills
5. Therapeutic playroom for high-risk newborns and infants
6. Drug & substance abuse counseling groups
7. Children and teen groups
8. Support for HIV affected individuals and families
9. Liaison nurse linking a local community hospital and the agency.

needs. For example, Table 6 shows the distribution of initial presenting problems at one of these agencies over a 30 month period.

TABLE 6 - PRESENTING PROBLEM
FAMILY HEALTH AGENCY
6,337 VISITS (30 MONTH PERIOD)

1. Entitlements, public ass't.	48.8%
2. Housing	30.3%
3. Emergency food	8.6%
4. Family problems	4.0%
5. Health related issues	1.9%
6. Job training, education	1.9%
7. Other (legal, immigration...)	1.4%

Note the relatively minor position occupied by 'Health Related Issues' at this Family Health Service agency among the multiple problems its clients face on a daily basis. Most of the services being sought and delivered are not insurance reimbursable.

In order to properly describe the services delivered, and to begin to derive a profile of service needs for this special population, it was necessary to capture far more information in retrievable form than is usually utilized for analysis of service utilization. Data are collected at each visit to the agency or to the client's home; the data collection instruments and methods of recording data are flexible enough to accommodate to many types of data. In addition, at every encounter, one or more outcomes is recorded as well as what type of follow-up is needed and what referrals, if any, are made. This applies to visits scheduled for a specific purpose and to informal 'drop-in' visits when the client comes to ask for or about something. Finally each visit measures the overall risk status of the client, with a numerical scale established and recorded, to serve as a flag for needed follow-up.

Most programs are resistant to the introduction of data collection because of staff's experience that data collection adds work with no payback for their efforts. Program specific data are often collected only to be shipped off in reports about which little feedback is provided to staff. With this program, staff soon begin to recognize that an integrated data-system minimizes the data that need to be collected and helps them to better understand the work that they are doing. Initially administration and staff most readily understand the value of the system for generating mandated reports, internal and agencywide lists and program and productivity analysis. Over time, they value its ability to provide them with the tools with which to do on-going assessment and program revisions.

In establishing and implementing the MIS system at all of these agencies, we have followed a schedule of actions and activities which is outlined in the following table.

TABLE 7 - IMPLEMENTATION OF MIS SYSTEM

1. Agency assessment and planning
2. Initial system specification
3. System design
4. Analysis of the flow of paperwork and forms revisions
5. Implementation
6. Reporting
7. On-going assessment/revisions of program
8. System enhancement - extensions- after the dust has settled
9. Evaluation, research and development.

This overall approach has been used at each type of site, with minor variations. There is no set timetable for any section of the implementation plan. Much depends on how ready the agency is to commit the appropriate level of resources in time, people and dollars to the project. It is instructive to examine elements of the initial step, Agency Assessment and Planning, as shown in Table 8.

TABLE 8 - AGENCY ASSESSMENT/PLANNING

1. Mandated reporting
2. Other reports needed for program operation
3a. Data currently collected - new and existing clients
3b. Data forms in use
4. Confidentiality of data - mandated or desired levels
5. Number of clients, number of visits, by program;
6. Source of referrals - accompanying paperwork
7. Survey of agency-wide distribution of information-- what is/is not shared with other programs - duplication of efforts.

Note that we start by examining in great detail the Reporting function of the system. We feel that it is mandatory to start at what is often considered the 'back end' of a system. After all, the object of installing a system is not to collect data, but to utilize the data for managing, planning and analyzing.

One of the most critical decisions which has to be made at the outset is to make certain that the data which are collected contain the appropriate 'units of measure' to enable proper analysis of the data at hand and, of greater importance, to allow linking of the datasets with other types of data and datasets. To do this one has to be aware of how other types of data which one will want to use to augment the local data are being collected and arranged.

For example, if you are going to utilize household income data as collected by the Census, then you have to be certain to incorporate a field in your client address database to identify the Census Tract corresponding to each address. As another example, epidemiologic data available from the New York City Department of Health are arranged by HSA area; in order to be able to link your data to the NYC data, each client address record should also include the HSA area. With respect to other units of measure such as ethnicity, country of origin, or country of birth, you may be collecting information which is much more detailed than the standard 5 ethnic groups used for much reporting, but you have to incorporate appropriate hooks in your data (this is very easy to do using small look-up databases) which will allow you to summarize your data into the standard 5 groups.

The system utilizes Alpha Four (Alpha Software) for data management and R&R Report Writer (Concentric Software) for all reporting. Both of these very sophisticated application programs are based on the dBASE file structure. We chose these application programs because of their nearly limitless flexibility - the system has to be able to quickly accommodate changes in database fields, display screens, and reporting requirements. A closed system which cannot be custom modified to suit needs of each agency simply will not be useful for any agency. It will serve only to record the same minimal core set of data from each agency, but in general will not give anything back to the agency.

At a family-based home health agency and for many other types of service agencies, services are generally delivered to individuals with:

(a) many individuals served by more than one program;
(b) many households containing more than one individual receiving services.

The file structure we utilize includes separate databases for HOUSEHOLD demographics and for INDIVIDUAL client demographics. A unique code for each household and for each client links the databases and enables tracking of all services provided to each client in all programs, and further, allows tracking of the totality of services provided to each household unit.

For each agency program, at least two program-specific databases are established; an INTAKE database to capture the data uniquely required by that program, and a VISIT/LOG database to record the daily (or weekly) activities of each client within the program. These databases differ from program to program since the tracking needs of an Education program are quite different from those of a Nursing program.

When we link the data for program VISITS to the INTAKE, INDIVIDUAL and HOUSEHOLD databases into a SET, we utilize the power of a relational database structure and can examine and analyze data using the very powerful selection, sorting, and subtotaling features of the Report Writer.

In Tables 10 and 11 we present examples of data extracted from the system for several different agencies.

TABLE 10 - DEMOGRAPHIC DATA
FAMILY HEALTH SERVICES

	AGENCY A 3.5 YRS	AGENCY B 18 MOS
Families	3,065	1,855
Individuals	7,701	5,200
Visits Walk-in	8,567	4,100
Outreach	3,400	
Nursing	4,800	
Ryan/White	2,200	
Mat/Child	1,100	
****		
ETHNIC GROUPS > 200		
Puerto Rican		
Afro American		
Mexican		
Dominican Republic		
Other Central American		
****		
HOUSEHOLD SIZE		
1 - 30%		
2 - 25% (high % single parents)		
3 - 18%		
4 - 11%		
5 - 5%		
>5- 11%		

1. Because of the substantial size of the various Hispanic subgroups, both agencies have been able to target their hiring, their outreach programs and their services very specifically. The very detailed visit records, for some clients spanning 3 years, allow us to see how identified problems are followed up and resolved and allow for modification of assessment criteria.

2. The maternal child project, which actually encompasses several different agency programs, allows detailed prenatal assessments and interventions of high risk mothers to be to be linked to follow-up newborn interventions and to identify new clusters of prenatal risk factors.

3. The data on the Ryan-White group of 280 individuals belonging to about 200 different households allows detailed analysis of the impact of HIV and AIDS on family units at various stages in the disease cycle.

Table 11 presents data for two different types of programs, a Needle Exchange and the Mount Sinai AIDS Center:

TABLE 11 - DEMOGRAPHIC DATA

	NEEDLE EXCHANGE	AIDS CENTER
INDIVIDUALS	> 12,000	3,628
VISITS	> 35,000	24,000
HOSPITALIZATIONS	N/A	4,844
NEEDLES DISTRIB	> 300,000	N/A
	****	
MALE	76%	64%
FEMALE	24%	36%
	****	
HISPANIC	51%	49%
AFRICAN AMERICAN	34%	36%
CAUCASIAN	14%	13%
OTHER/UNKNOWN	1%	2%

1. It is interesting to note that the ethnic distribution of both populations is nearly identical, but females are under-represented at the Needle Exchange. On the basis of an analysis of the minimal datasets collected at the exchange which examined utilization and retention rates of clients, we were able to obtain a grant for a TB DOPT program sited at the Needle Exchange field location, which has served as a pipeline to medical, social services and drug treatment services.

2. The AIDS Center databases cover both clinic visits and hospitalizations, thus allowing us to follow the course of the patients and the disease in a greater level of detail than if one were to look only at inpatient or outpatient data - for example comparing those whose first contact was through the Clinic with those who were first hospitalized.

As each program has become operational, the CBO has experienced the standard (and anticipated) reaction to the availability of computerized reports, namely, a desire to modify aspects of their operating procedures and data collection in response to a recognition that they *could now ask questions of the data* which were virtually impossible when using paper records only. As a result, each program's individualized databases and associated reports have been revised an average of twice a year.

From these examples we see that each agency is increasingly able to utilize agency-wide reporting to plan for future needs. (The needle exchange program was able to seek and obtain Ryan White funding to develop a TB screening and preventive therapy program; the Mental Health Program has been able to obtain additional funding; one of the two Family Health Services agencies is linking Ryan White Title I and Title IV program data, the AIDS Center program has been able to modify existing forms and data-sets to capture new information required by outside auditors).

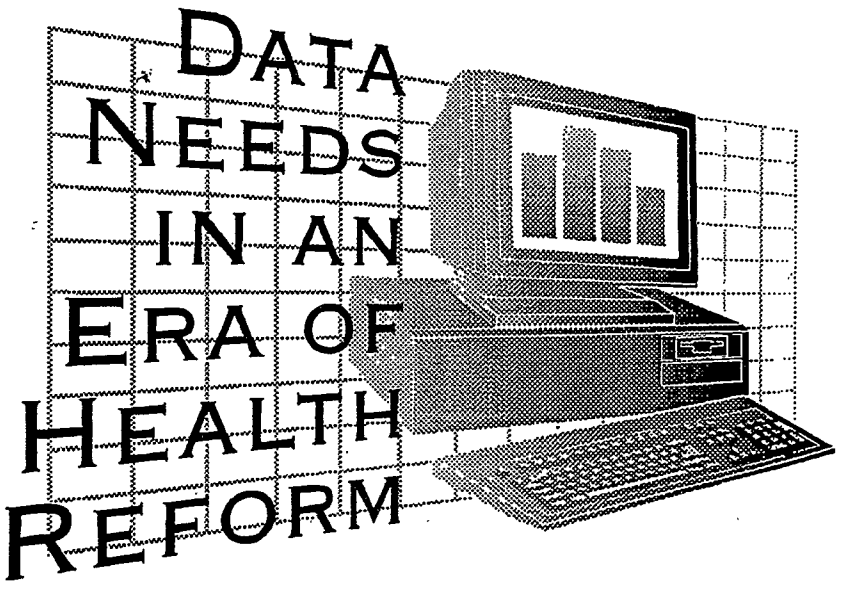
CONCLUSIONS

Large and small agencies have been grappling with the information revolution that is allowing and forcing the collection and organization of masses of data and the detailed reporting of program activities and resources. The advent of PCs and powerful data-base and reporting software, if supported by sustained technical assistance from social scientists and system analysts, allows the smallest agencies to organize, analyze and modulate and expand programs to meet internal and external forces. The technology is available which allows small agencies to manage and analyze complex data. However, to facilitate the adoption of this approach requires the development of collaboration among agency program and administration, and a consultation team that provides sustained program, staff, resource and data development and evaluation support.

This paper offers a feasible approach for harnessing and the utilizing these strategic grassroots sites involved in upstream work with special populations as sites in which to collect and aggregate rich local geographic information to monitor and assess and address the emergent needs in vulnerable communities and regional areas.

Session X

Data Integrity



HOSPITAL REPORTING PRACTICES AND THEIR IMPACT ON TEXAS BIRTH CERTIFICATE DATA QUALITY

Mary K. Ethen, Texas Department of Health
Beatrice J. Selwyn and Stephen B. Borders

In 1989, following national recommendations, the Texas birth certificate was extensively revised (1). The certificate now includes a series of check box items to collect information on more than 50 specific medical conditions and procedures related to pregnancy, childbirth and the health of mothers and newborns (see Appendix). This was intended to provide data for public health monitoring, community health needs assessment, epidemiologic research, and program planning and evaluation.

This paper presents the results of two surveys related to birth certificate data quality. The first survey evaluates the completeness and accuracy of birth certificate data, and the second survey describes hospital practices for collecting birth certificate information which affect data quality. Based on these studies, recommendations are presented for improving the quality of health-related information collected via birth certificates.

VALIDATION OF BIRTH CERTIFICATE DATA

The first survey arose as a preliminary investigation for a larger project that proposed to use the new health and medical information on birth certificates to identify risk factors for infant mortality and other adverse pregnancy outcomes in a metropolitan area of Texas. However, before using the new data for this purpose, the investigators decided to first assess the validity of the health and medical information reported on birth certificates in comparison to hospital medical records.

Methods

Sample Selection and Data Collection Procedures

We restricted the study to births that occurred during 1991 in the six largest hospitals in the county of interest. These six hospitals accounted for more than half of all births in the county. We selected a systematic probability sample of 443 total live births, one out of every 74 deliveries in the each of the six target hospitals. In this way, the number of births selected from each hospital was proportional to the total number of live births in that hospital.

For each birth selected, we requested the newborn's and the mother's hospital medical records. Without knowledge of what had been reported on the birth certificate, trained abstracters carefully reviewed both the mother's and the infant's medical records for 421 (95 percent) of the births selected. Abstracters entered data from the medical records directly into laptop computers while at the hospital, using computerized data collection instruments designed in Epi Info version 5.01B (2). Range and logic checks were run at the time of data entry, which allowed us to detect and correct many potential errors and logical inconsistencies while we had the medical records in hand. The data abstracted from the medical records were then matched to computerized birth certificate data for the same birth, and the two sources of information were compared for similarity.

Measures of Data Validity

We used three measures to assess the validity of birth certificate information in comparison to medical records data (Table 1). The first measure, which was calculated for each item of information collected, is percent agreement. Percent agreement is the percentage of births reviewed for which the information reported on the birth certificate agreed with what we found in the medical records.

For the medical conditions and procedures reported on the birth certificate using check boxes, percent agreement consists of two types of agreement: births for which the birth certificate and medical records both indicate that a given condition or procedure existed, plus births for which the two sources indicate that the condition or procedure did *not* exist. Because most births are normal and without complications, there are many births for which the birth certificate and the medical records will agree that given conditions or procedures did *not* exist. This results in high levels of agreement between birth certificates and medical records for most medical conditions, simply because most of the reportable conditions are rare.

For this reason two additional measures of data validity, sensitivity and predictive value positive, were used to evaluate the medical information reported on birth certificates (Table 1). Sensitivity is the fraction of births with a given condition according to the medical records which had that condition reported on the birth certificate. Sensitivity indicates completeness of case identification on the birth certificate. Predictive value positive is the fraction of births with a given condition reported on the birth certificate which had that condition according to the medical records. Predictive value positive indicates accuracy of case identification on the birth certificate.

Table 1
Measures of birth certificate data validity

1. Percent Agreement:

$$\frac{\text{number of births for which birth certificate \& medical records agree}}{\text{number of births reviewed}} \times 100$$

- Indicates *similarity* of birth certificate and medical records information

2. Sensitivity:

$$\frac{\text{number of births with condition reported in medical records and on birth certificate}}{\text{number of births with condition reported in medical records}}$$

- Indicates *completeness* of case identification on the birth certificate

3. Predictive value positive:

$$\frac{\text{number of births with condition reported in medical records and on birth certificate}}{\text{number of births with condition reported on birth certificate}}$$

- Indicates *accuracy* of case identification on the birth certificate

Results

We found 97 to 100 percent agreement between the birth certificate and corresponding medical records for basic information such as date of birth, sex, birth weight and mother's date of birth (Table 2). Method of delivery and last menstrual period date were less accurately reported on birth certificates: each showed 82 percent agreement with medical records data. Only 53 percent of the birth certificates reviewed agreed with the medical records for the month of pregnancy prenatal care began.

Most of the medical conditions and procedures reported on the certificate via check boxes fell in the range of 80 to 90 percent agreement. This agreement consisted almost entirely of normal, uncomplicated pregnancies for which the birth certificate and medical records both indicated that various conditions did not exist.

Table 2
Percentage of births with agreement between birth certificate and medical records data, Texas, 1991

Data item	% agreement
Sex	100
Date of birth	99
Birth weight (within ±1 oz. or ±28 g.)	97
Mother's date of birth	97
Method of delivery†	82
Last menstrual period date (month and year only)	82
Month prenatal care began (within ±1 month)	53

† vaginal, vaginal after previous C-section, primary C-section or repeat C-section

To assess how often specific conditions and procedures documented in the medical records were reported on the birth certificate, we computed sensitivity (see Table 1 for definition). For example, we found 33 mothers who had diabetes according to their medical records; only 15 of them had diabetes reported on the birth certificate (Table 3). We found 26 mothers with pregnancy-associated hypertension according to their medical records; only 7 of these were reported on the birth certificate. Only 5 of 60 cases of a sexually transmitted disease during pregnancy were reported on the birth certificate. Sensitivity was zero percent for 24 reportable conditions and procedures, including previous preterm or small-for-gestational-age infant, tocolysis, and dysfunctional labor.

To evaluate how often conditions and procedures reported on the birth certificate were verified by the medical records, we computed predictive value positive (for definition see Table 1). There were 29 birth certificates with induction of labor reported, but only 15 of these were induced according to the medical records (Table 3). Only 3 of 9 reports of a fever during labor were documented in the medical records. Predictive value positive was very high for fetal monitoring: 188 of 196 cases reported on the birth certificate were confirmed by the medical records. However, the sensitivity for fetal monitoring was low. According to the medical records, 410 women received fetal monitoring; only 188 of these were reported on the birth certificate.

Predictive value positive was 100 percent for 6 conditions, including diabetes and pregnancy-associated hypertension, meaning that all of the cases reported on the birth certificate were confirmed by the medical records. At the other extreme, predictive value positive was zero percent for 11 conditions, meaning that none of the cases reported on the birth certificate were supported by the medical records. However, all 11 conditions with zero percent predictive value positive were reported on the birth certificates in our sample no more than 4 times.

These findings indicate that, for most conditions and procedures, only a portion of the cases documented in the medical records were reported on the birth certificate; for many conditions, none of the cases found in the medical records were reported on the certificate. Furthermore, conditions reported on the birth certificate were not always corroborated by the medical records.

BIRTH CERTIFICATE REPORTING PRACTICES SURVEY

We recognized that there was a problem getting health-related information from the medical records onto birth certificates, but we didn't know exactly where the breakdown was occurring. In order to gather information on birth certificate reporting practices that affect data quality, a telephone survey of personnel responsible for preparing birth certificates in hospitals throughout Texas was conducted in 1994.

Methods

Live births were reported in 328 Texas hospitals in 1993. Our strategy was to survey more of the hospitals that prepare a large number of birth certificates and fewer hospitals that prepare a small number of birth certificates. We excluded from the survey hospitals with 50 or fewer births per year (n=63 hospitals), because they averaged less than 1 birth per week and contributed only 0.2 percent of all 1993 Texas occurrence births. The remaining 265 hospitals were divided into four groups (strata) based on number of births in 1993, with cut-points between strata chosen to most closely satisfy the following guideline: 2 times the division point between stratum x and stratum $(x+1)$ should equal the mean number of births in stratum x plus the mean number of births in stratum $(x+1)$ (3,pg.96).

From each group, we selected a number of hospitals proportional to the percentage of births that occurred in all hospitals belonging to that group (Table 4). For example, we found that 10 percent of all births occurred in hospitals with 51 to 600 births per year, so we made sure that 10 percent of our sample consisted of hospitals of that size. In this way, our sample was weighted to represent the distribution of Texas births according to hospital size. Our total sample size was limited to 71 hospitals by the fact that 44 percent of all Texas in-hospital births occurred in the 31 largest hospitals (31 equals 44 percent of 71). The 31 largest hospitals were all selected for the survey, and a systematic sample of hospitals was selected from within each of the other three strata.

We telephoned each selected hospital, invited the staff member responsible for preparing birth certificates to participate, and scheduled a convenient time to call back and conduct the interview. Hospital personnel were asked questions about the methods they use to collect and report birth certificate information, and about their education, experience and training. Interviews lasted approximately 30 minutes and were completed with 69 of the 71 hospitals selected, for a 97 percent response rate. The hospitals surveyed were located throughout the state and contributed 57 percent of all 1993 Texas births. Public hospitals, private not-for-profit hospitals, private for-profit hospitals and military hospitals were all represented in the survey.

Table 3
Sensitivity† and predictive value positive† for selected health and medical information reported on the birth certificate using check boxes, Texas, 1991

Data item	Sensitivity	Predictive value positive
Maternal Medical Risk Factors		
Maternal anemia	2/50	2/7
Cardiac disease	0/9	
Lung disease	0/15	
Diabetes	15/33	15/15
Hydramnios/ oligohydramnios	0/25	
Hemoglobinopathy	0/2	
Chronic hypertension	2/8	2/2
Pregnancy-associated hypertension	7/26	7/7
Eclampsia		0/1
Previous infant 4000+ grams	0/21	0/1
Previous preterm or small-for-gestational-age infant	0/31	0/2
Renal disease	0/12	
Rh sensitization	0/3	0/4
Preterm rupture of membranes (<37 wks)	1/42	1/3
Sexually transmitted disease	5/60	5/6
Obstetric Procedures		
Amniocentesis	10/42	10/15
Fetal monitoring	188/410	188/196
Induction of labor	15/71	15/29
Stimulation of labor	5/206	5/8
Tocolysis	0/22	0/2
Ultrasound	138/305	138/170
Complications of Labor and Delivery		
Febrile	3/22	3/9
Meconium, moderate or heavy	11/39	11/28
Abruptio placenta	1/6	1/1
Placenta previa	1/4	1/1
Other excessive bleeding	0/3	0/1
Seizures during labor		
Precipitous labor	1/10	1/4
Prolonged labor	0/15	
Dysfunctional labor	0/52	0/1
Breech/malpresentation	8/33	8/11
Failure to progress in labor (cephalopelvic disproportion)	7/12	7/11
Cord prolapse	0/1	0/1
Abnormal Conditions of the Newborn		
Fetal alcohol syndrome		
Hyaline membrane disease/respiratory distress syndrome	0/11	0/1
Meconium aspiration syndrome	1/2	1/12
Assisted ventilation <30 minutes	3/22	3/19
Assisted ventilation 30+ minutes	0/11	0/3
Seizures	0/1	
Congenital Anomalies of the Newborn		
Anencephalus		
Spina bifida/meningocele		
Hydrocephalus		
Microcephalus	0/1	
Other central nervous system anomalies		
Heart malformations	0/4	
Other circulatory/ respiratory anomalies	0/8	
Rectal atresia/stenosis		
Tracheo-esophageal fistula /esophageal atresia		
Omphalocele /gastroschisis	0/9	
Other gastrointestinal anomalies	1/9	1/1
Malformed genitalia	0/8	
Renal agenesis		
Other urogenital anomalies		
Cleft lip/palate	0/1	
Polydactyly/syndactyly	0/2	
Limb reduction(s)		0/1
Club foot		
Diaphragmatic hernia		
Other musculoskeletal/ integumental anomalies	0/4	
Down's syndrome		
Other chromosomal anomalies		

† See Table 1 for definitions. A blank for sensitivity means there were no occurrences in the medical records. A blank for predictive value positive means there were no occurrences on the birth certificate.

Results

The hospital employee responsible for preparing birth certificates is usually a medical records clerk or a ward clerk in the maternity department. Birth certificate clerks have a median of 13 years of education (Table 5). Thirty-eight percent have no more than a high school education; 10 percent have completed college.

Nearly one-quarter of the personnel surveyed have less than one year's experience preparing birth certificates, which indicates the rate of turnover in these positions (Table 5). The median longevity is three years.

With the turnover in these positions, it's not surprising that the majority of birth certif-

Table 4
Hospital stratification and sample selection

Hospital size according to births in 1993	Total hospitals	% of total 1993 hospital births	Hospitals selected #	Hospitals selected % of sample
51-600	118	10%	7	10%
601-1500	82	24%	17	24%
1501-2900	34	22%	16	22%
2901+	31	44%	31	44%
Total	265	100%	71	100%

Table 5
Education and experience of hospital clerks who prepare birth certificates, Texas, 1994

	% of hospitals surveyed
Years of education completed	
11 to 12	38
13 to 15	51
16 or more	10
Median: 13 years	
Years preparing birth certificates	
less than 1	23
1 to 3	28
4 to 8	25
9 or more	25
Median: 3 years	

Percentages may not sum to 100 due to rounding.

Table 6
Who taught hospital clerks to prepare birth certificates, Texas, 1994

	% of hospitals surveyed
Predecessor	66
Supervisor	35
Self-taught	34
Vital statistics field rep	19
Local registrar	18
Vital statistics conference	13
Employee of another hospital	12

Multiple responses allowed, percentages sum to greater than 100.

icate clerks were trained by their predecessors or their supervisors, or taught themselves using written instructions from the Texas Bureau of Vital Statistics (Table 6). Nineteen percent said they were taught by the vital statistics field representative, and 13 percent said they learned at the annual vital statistics conference.

Since clerical personnel are responsible for preparing birth certificates, we asked survey respondents whether anyone summarizes the health and medical information they need for the certificate. We categorized hospitals according to the most highly trained staff member who provides health and medical information for birth certificates. We found that a physician or nurse provides the medical data in 48 percent of hospitals surveyed, a medical records coder supplies this information in 3 percent of hospitals, and in 49 percent of hospitals, the birth certificate clerk collects the medical information by checking the patient's records (Table 7).

While physicians and nurses summarize the medical data in 48 percent of hospitals surveyed, these hospitals contributed only 40 percent of all births that occurred in the surveyed hospitals (Table 7). Fifty-eight percent of total births occurred in facilities where a clerk collects the health and medical information required for the certificate.

We asked respondents to estimate the total number of hours per week that all birth certificate clerks employed by the hospital spend working on any aspect of birth certificate preparation. For each hospital surveyed, we

Table 7
Distribution of hospitals and births, according to most highly trained staff member who provides health and medical information for birth certificates, Texas, 1994

Staff member who provides health and medical information	% of hospitals surveyed	% of total births in hospitals surveyed
Clerk	49	58
Physician or nurse	48	40
Medical records coder	3	3
Total	100	100

Percentages may not sum to 100 due to rounding.

Table 8
Time needed to prepare one birth certificate, Texas, 1994

Hospital size (births per year)	Median time spent per birth certificate
Small (51-600)	69 minutes
Medium (601-1500)	56 minutes
Large (1501-2900)	52 minutes
Very large (2900+)	40 minutes
All hospitals surveyed	45 minutes

related clerk-hours to the number of births in the hospital to calculate the average time needed to complete one certificate.

The median value of the averages from each of the hospitals surveyed was 45 minutes per birth certificate (Table 8). The amount of time spent per certificate was inversely proportional to the number of births in the hospital: smaller hospitals devoted more time to birth certificates; larger hospitals devoted less time.

To estimate the cost of preparing birth certificates, we multiplied the median time of 45 minutes per certificate by the average 1993 starting wage of $5.68 per hour for clerk-typists in Texas hospitals (4,pg.29). We found that birth certificates cost hospitals a minimum of $4.26 each to prepare (Table 9). This is a minimum estimate, and does not include other costs such as fringe benefits, overhead expenses, supplies and equipment, or the time spent by physicians, nurses and other staff members who provide information for birth certificates.

Multiplying the minimum cost of $4.26 per certificate by 318,642 in-hospital births, we found that birth certificate preparation cost Texas hospitals more than 1.35 million dollars in 1993 (Table 9).

SUMMARY OF FINDINGS OF THE TWO STUDIES

To recap, we learned that health and medical information reported on birth certificates showed fair levels of agreement with medical records, but most of the agreement was among normal, uncomplicated pregnancies. When medical conditions or procedures existed according to the hospital records, only a fraction of the cases were reported on the birth certificate. Further, conditions reported on birth certificates were not always confirmed by the hospital records.

Table 9
Cost of birth certificate preparation, Texas, 1993

45 minutes/certificate x $5.68/hour =
⇒ $4.26 per birth certificate

$4.26/certificate x 318,642 in-hospital births =
⇒ over $1.35 million per year

Health and medical information for birth certificates is often collected by clerical workers. Wages are low, there is regular turnover in these jobs, and most clerks were taught to complete birth certificates by the person who held the job before them.

Birth certificate preparation requires considerable time and money. In spite of low wages, birth certificates cost Texas hospitals over 1.35 million dollars per year; this figure does not include the costs borne by local registrars, the state vital statistics office, or the National Center for Health Statistics. Substantial amounts of time and money are being spent collecting data that are of poor quality.

These findings are not unique to Texas. Comparable results have been published on the validity of birth certificate data in Tennessee (5), North Carolina (6), and Washington State (7,8). All states collect a similar array of information, and all states are susceptible to the same data quality problems.

RECOMMENDATIONS FOR IMPROVING BIRTH CERTIFICATE DATA QUALITY

The results of these two surveys have led us to several ideas for improving the completeness and accuracy of health-related information on birth certificates (Table 10). One method of improving the data is by providing more training for those who complete certificates. Because of job turnover, training programs need to be available on a regular basis. Training could be done via satellite, via tutorials built into computer programs used to generate birth certificates, or face-to-face. Periodic audits of a sample of birth certificates are useful to identify specific problems and help hospitals develop plans to improve data quality.

Clinicians could receive training regarding their responsibilities during medical or nursing school, during internships and residencies, or through continuing education courses.

The birth certificate requests information on more than 50 specific medical conditions and procedures. If we cannot collect this information accurately and completely, we should consider reducing the amount of information collected. Floyd Frost and colleagues from Washington State noted in 1984 that "it is probably more useful to have relatively complete information on a limited number of conditions than to have very incomplete information on a larger number of conditions" (9,pg.506).

Perhaps we should carefully review and revise the birth certificate, keeping only those items most important from a public health point of view, then concentrate on collecting accurate information on a smaller set of conditions.

Another option would be to collect extensive medical information on a sample of births. We could have a short form of the certificate, without the medical information, which would be used routinely, plus a long form, including the health and medical data, to be used on a sample of births. Because the short form would take less time to complete, and medical information would only be required on selected births, hospitals should be able to devote more staff time or more highly trained staff members to collect the medical information. We might also consider doing away with the medical information on birth certificates altogether and collecting it through special sample surveys.

Table 10
Recommendations for improving birth certificate data quality

- Provide more training for those who complete birth certificates
- Reduce the amount of information collected via birth certificates
- Increase time devoted to birth certificates and qualifications of staff who complete birth certificates
- Automate and integrate birth certificate data collection into computerized patient medical records

A third idea for improving the quality of birth certificate data is to encourage hospitals to devote more staff time or more highly trained staff members to birth certificate preparation. There will probably be resistance to this, as birth certificate preparation is not a revenue-generating activity, and facilities are facing financial challenges. After formal training programs are established, we might consider requiring credentials to prepare birth certificates. We might also approach accrediting agencies to tie birth certificate accuracy into facility accreditation.

Currently Texas and other states have stand-alone computer programs used to print birth certificates and to relay the data to the state electronically. The next step is to integrate birth certificate preparation into computerized patient records. Programs can be written to automatically extract relevant information from computerized medical records, and place that information onto the birth certificate. The certificate can become a by-product of patient care, rather than a special effort. Automation will reduce the time needed to prepare certificates and increase data quality. This will be a challenge, but it probably has the greatest likelihood for payoffs, because it will increase data quality while streamlining hospital operations. Now, as computerized medical record systems are being developed, is the critical time for vital statistics offices to work with hospitals and software vendors to integrate birth certificates into computerized medical records systems.

Forty-four years ago, A.M. Lilienfeld and colleagues from the New York State Department of Health noted that "the value of [routine collection of morbidity statistics] depends upon the accuracy of the reported data and extent of under-reporting" (10,p.191). The current data reporting methods are not providing us with accurate and complete information. State vital statistics offices, departments of health, and the National Center for Health Statistics must work with hospitals to improve the completeness and accuracy of public health information collected via birth certificates. The best solutions are those which offer benefits to both the data providers and the data users. Until reporting methods and data quality are improved, birth certificate medical information must be used with great caution.

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Appendix

Health and medical information added to the Texas birth certificate in 1989

34a. MEDICAL FACTORS FOR THIS PREGNANCY
(Check all that apply)

- None ..... 01☐
- Unknown ..... 02☐
- Anemia (Hct.<30/Hgb.<10) ..... 03☐
- Cardiac disease ..... 04☐
- Acute or chronic lung disease ..... 05☐
- Diabetes ..... 06☐
- Hydramnios/Oligohydramnios ..... 07☐
- Hemoglobinopathy ..... 08☐
- Hypertension, chronic ..... 09☐
- Hypertension, pregnancy-associated ..... 10☐
- Eclampsia ..... 11☐
- Incompetent cervix ..... 12☐
- Previous infant 4000 + grams ..... 13☐
- Previous preterm or small-for-gestational-age infant ..... 14☐
- Renal disease ..... 15☐
- Rh sensitization ..... 16☐
- Preterm rupture of membranes (<37 weeks) ..... 17☐
- STD ..... 18☐
- Other _____ 19☐ (Specify)

34b. OTHER FACTORS FOR THIS PREGNANCY
(Complete all items)

- Tobacco use during pregnancy ..... Yes☐ No☐
  Average number cigarettes per day ____
- Alcohol use during pregnancy ..... Yes☐ No☐
  Average number drinks per week ____
- Pre-pregnancy weight _____ lbs.
- Weight gained during pregnancy _____ lbs.

35. OBSTETRIC PROCEDURES
(Check all that apply)

- None ..... 20☐
- Amniocentesis ..... 21☐
- Electronic fetal monitoring ..... 22☐
- Induction of labor ..... 23☐
- Stimulation of labor ..... 24☐
- Tocolysis ..... 25☐
- Ultrasound ..... 26☐
- Other _____ 27☐ (Specify)

36. EVENTS OF LABOR AND/OR DELIVERY
(Check all that apply)

- None ..... 28☐
- Febrile (>100°F. or 38°C.) ..... 29☐
- Meconium, moderate/heavy ..... 30☐
- Premature rupture of membrane (>12 hours) ..... 31☐
- Abruptio placenta ..... 32☐
- Placenta previa ..... 33☐
- Other excessive bleeding ..... 34☐
- Seizures during labor ..... 35☐
- Precipitous labor (<3 hours) ..... 36☐
- Prolonged labor (>20 hours) ..... 37☐
- Dysfunctional labor ..... 38☐
- Breech/Malpresentation ..... 39☐
- Failure to progress in labor ..... 40☐
- Cord prolapse ..... 41☐
- Other _____ 42☐ (Specify)

37. METHOD OF DELIVERY
(Check all that apply)

- Vaginal ..... 43☐
- Vaginal birth after previous C-section ..... 44☐
- Primary C-section ..... 45☐
- Repeat C-section ..... 46☐
- Forceps ..... 47☐
- Vacuum ..... 48☐

38. ABNORMAL CONDITIONS OF THE NEWBORN
(Check all that apply)

- None ..... 49☐
- Anemia (Hct.<39/Hgb.<13) ..... 50☐
- Fetal alcohol syndrome ..... 51☐
- Hyaline membrane disease/RDS ..... 52☐
- Meconium aspiration syndrome ..... 53☐
- Assisted ventilation <30 min. ..... 54☐
- Assisted ventilation ≥30 min. ..... 55☐
- Seizures ..... 56☐
- Other _____ 57☐ (Specify)

39. CONGENITAL ANOMALIES OF CHILD
(Check all that apply)

- None noted ..... 58☐
- Anencephalus ..... 59☐
- Spina bifida/Meningocele ..... 60☐
- Hydrocephalus ..... 61☐
- Microcephalus ..... 62☐
- Other central nervous system anomalies (Specify) _____ 63☐
- Heart malformations ..... 64☐
- Other circulatory/respiratory anomalies (Specify) _____ 65☐
- Rectal atresia/stenosis ..... 66☐
- Tracheo-esophageal fistula/Esophageal atresia ..... 67☐
- Omphalocele/Gastroschisis ..... 68☐
- Other gastrointestinal anomalies (Specify) _____ 69☐
- Malformed genitalia ..... 70☐
- Renal agenesis ..... 71☐
- Other urogenital anomalies (Specify) _____ 72☐
- Cleft lip/palate ..... 73☐
- Polydactyly/Syndactyly ..... 74☐
- Limb reduction(s) ..... 75☐
- Club foot ..... 76☐
- Diaphragmatic hernia ..... 77☐
- Other musculoskeletal/integumental anomalies (Specify) _____ 78☐
- Down's syndrome ..... 79☐
- Other chromosomal anomalies (Specify) _____ 80☐
- Other _____ 81☐ (Specify)

TECHNIQUES FOR COMBINING QUALITATIVE AND QUANTITATIVE DATA TO IMPROVE THE VALIDITY, RELIABILITY, AND COMPARABILITY OF HEALTH SURVEYS

Carol N. D'Onofrio, Northern California Cancer Center
Susan L. Stewart, Rena J. Pasick, Joyce A. Bird, Joan R. Bloom

Rapid changes in the racial and ethnic composition of the U.S. population are accompanied by increasing linguistic and cultural heterogeneity. Due to heavy migration, the San Francisco Bay Area enjoys a particularly rich mix of peoples from diverse racial, ethnic, cultural, and linguistic backgrounds.

As public health investigators who regularly survey this population, we began to question the extent to which health data collected from multi-ethnic, multi-lingual people living in the same geographic region are valid, reliable, and comparable. In 1992, we received a grant from the National Center for Health Statistics to study this question.

This paper briefly describes the various qualitative and quantitative research techniques independently employed to identify potential methodological problems affecting the quality of data collected from five racial/ethnic groups: African American, Chinese, Latina, Vietnamese, and white. We then illustrate methods for combining results of qualitative and quantitative data analysis to determine whether discrepancies observed represent real population differences or bias due to methodological problems. We also discuss some of the techniques we are using to isolate methodological difficulties and to test potential solutions to these problems.

We do not presume to have definitive answers to the issues raised by this work, but we have identified some promising directions for their continuing study.

Background

Our project is a methodological investigation coordinated with three intervention studies funded by the National Cancer Institute. All three intervention studies are aimed at improving breast and cervical cancer screening among low-income women and ethnic minorities living in the San Francisco Bay Area. Each of these studies is conducted by a multi-disciplinary team with strong representation from the targeted racial/ethnic groups and close ties to their respective communities. Important for our purposes, all three studies also collect data from these communities in pre- and post-intervention surveys.

Since two of the three projects were initiated one year before our NCHS project was funded, our work with these studies was retrospective. The Breast and Cervical Cancer Intervention Study (BACCIS) conducted household interviews with low-income women living in census tracts near health department clinics in two counties. The baseline survey in 1992-93 yielded 1,599 completed interviews, including 475 with African Americans, 279 with Chinese, 230 with Latinas, 500 with whites, and 115 with women from other racial and ethnic groups. Chinese respondents completed the survey in English, Cantonese, or Mandarin, and Latina respondents were offered a choice of Spanish or English.

During the same period, the Vietnamese Prevention Study (VPS) conducted baseline telephone interviews with 933 Vietnamese women living in San Francisco and Orange Counties. All of these interviews were conducted in Vietnamese.

The Pathways project was initiated in the same year as our NCHS investigation and thus we could track each stage of survey development and implementation prospectively. Pathways is a multi-component program project consisting of independent community intervention studies with Latinas and Vietnamese women, another intervention study in a hospital Emergency Department that serves mostly African Americans, a population survey of Chinese Americans, and a shared cross-cultural core.

Working through this core, common questions were developed for use in surveying African American, Chinese, Latina, Vietnamese, and white women.[1] Since breast and cervical cancer screening rates are high among African American and white women in the San Francisco Bay Area, these populations were surveyed for comparison purposes only. In summer and fall 1993, data were obtained from 1,601 Latinas, 645 Vietnamese, 775 Chinese, 602 African American, and 605 white women. As in BACCIS, Chinese and Latina participants in Pathways surveys were offered a choice of language.

Preliminary Methods

The first step in our NCHS project was to distinguish variables that seemed to work well across populations from those that appeared troublesome. We approached this task independently through both qualitative and quantitative routes.

On the qualitative side, we interviewed investigators who developed the survey questionnaire for each of the three intervention studies, those who translated and back-translated the various surveys into Spanish, Cantonese, Mandarin, and Vietnamese, and the bi-lingual survey workers who actually collected data in English or one of these other languages.

Prior to these interviews, we asked each of these people to rate each question on their respective survey on three dimensions which varied with their research role. Survey workers, for example, were asked to rate how easy or difficult it was to ask each question, how easy or difficult they thought it was for respondents from their respective ethnic groups to answer it, and the question's appropriateness in their own particular culture. Written comments were encouraged on the rating form.

Interviews were organized around a systematic review of each survey instrument, with in-depth discussion of questions identified as troublesome in written rating forms and comments. Pretest results and subsequent revisions were also discussed with those who designed and translated the questionnaire for each survey.

Resulting qualitative data enabled us to identify problematic questions and variables within each survey and ethnic/racial group. Once this was done, results were consolidated to identify variables that were troublesome across

surveys and racial/ethnic groups.

While this work was in progress, the principal investigators and statisticians for each intervention study proceeded with quantitative analysis of their survey data. They used standard techniques for examining the distribution of the data, bivariate, and then multi-variate relationships. Variables with missing data from many respondents and those that did not behave as expected in analysis were independently identified as potentially problematic.

Our NCHS project enabled us to have interviewers call back a 10% random sample of respondents from the five ethnic groups surveyed for Pathways. To check reliability of responses, the brief callback questionnaire repeated four questions from the original Pathways survey. Respondents also were asked whether they found certain questions embarrassing, offensive, or difficult. Then they were asked how likely most people were to answer these questions truthfully. These data provided additional insight into issues related to a few specific questions identified as troublesome early in our investigation.

Income: A Troublesome Variable

Our work with survey questions on income illustrates many of the ways we have combined qualitative and quantitative data in analysis.

Our qualitative work with the BACCIS and VPS surveys quickly identified income as a variable difficult to measure within and across racial/ethnic groups. In fact, this variable posed so many problems, that Pathways investigators decided to collect income data in two ways. Fortuitously for our NCHS project, this decision embodied an important technique for improving health surveys--the testing of alternative questions forms. However, this natural experiment had a limitation: the order in which questions were presented was not randomly varied.

The first Pathways income question aimed simply to determine whether the respondent's family lived above or below the poverty level. This was preceded by a question inquiring about family household size. The interviewer then used a chart to determine the poverty line for a family of that size and simply asked the respondent whether the combined monthly income of the family was more or less than that amount. The second question simply asked respondents to estimate the approximate total income of household members for the last tax year.

These questions came near the end of the interview and were prefaced by a statement acknowledging that it is difficult to estimate income, but that this information is important in understanding the need for health care assistance in the respondent's ethnic community. Assurances about the confidentiality of information provided in the interview were repeated.

Qualitative Data on Income Questions

Qualitative data from the Pathways survey revealed many problems with both of these questions. Across ethnic groups we were told many people did not like to reveal their income. They did not understand why this information is relevant to studying health, and they worried about how the data would be used.

We also were told that Chinese would underestimate their income and that Vietnamese would not provide truthful responses. Those who interviewed Latinas complained that the income questions were difficult because people had to stop and think. Determining household size for the poverty question was a complex task for immigrants who doubled up with other families to save money, and for all respondents whose older children and extended family members sometimes lived with them.

Interviewers from all racial/ethnic groups did not like the income questions because they interfered with respondent rapport and the pace of the interview. If respondents refused to answer the question about poverty level, interviewers also felt uncomfortable asking the next question about estimated family income.

Missing Data Rates

Problems with the Pathways income questions also showed up as soon as analysts ran frequency distributions. Considering both refusals and don't know responses, the missing data rate for most questions was less than 5%, but missing data on the two income questions ranged from 10-22% for all groups except the Vietnamese. These results would have been difficult to interpret without qualitative data from Vietnamese interviewers indicating their people from their community would "give a number", but it would be wrong.

In every racial/ethnic group, respondents were more likely to answer the dichotomous question on poverty status than the more detailed question on income. As Table 1 shows, respondents who disclosed their income almost always answered the question on poverty status. In addition, a fair proportion of people who would not estimate their annual family income indicated whether their family lived above or below poverty level. Still, from 4-11% of each racial/ethnic sample answered neither question.

Table 1. Percentage Answering Poverty Status and Income Questions

	Both	Only Poverty	Only Income	Neither
African-Amer.	82	8	1	9
Chinese	80	10	1	8
Latina	76	11	2	10
Vietnamese	93	2	-	4
White	82	6	6	11

Therefore we asked, What are the characteristics of people who do not provide information about income? Why are they not answering? How good are the data on income that we did obtain?

Who Doesn't Answer Questions about Income?

Due to their low rate of missing data on poverty status and income, Vietnamese were excluded analyses of characteristics associated with missing data on these variables. In all other groups, older respondents and those with less than 12 years of education were least likely to answer the income question. Blacks and Chinese with five or more in their households also were likely to have missing income data. (See Table 2).

Age and household size had the same relationship to missing data on poverty level.

However, education was related to missing data on poverty level only for Hispanics.

These quantitative results were consistent with our qualitative data. For example, we were told that older Chinese women live with an adult son and they don't know or care how much he makes. Among African Americans, older women on social security and widows were most suspicious about the income questions. Some African American respondents told interviewers it was impolite to ask about income.

Table 2. Variables Related to Missing Data on Annual Family Income

	Age	Education	Household Size
African-Amer.	0.001	0.01	0.001
Chinese	0.001	0.001	0.004
Latina	0.001	0.001	
White	0.001	0.01	

Callback Interviews

Callbacks to a 10% random sample of persons from each racial/ethnic group who had completed the Pathways questionnaire provided additional insight on why some people did not provide data on income. A sizable proportion of respondents considered these questions embarrassing, offensive, and difficult. As Table 3 shows, Chinese, Latina, and Vietnamese respondents were much more likely to consider these questions difficult than embarrassing or offensive.

Table 3. Percentage Saying Income Questions Very or Somewhat

	Embarrassing	Offensive	Difficult
African-Amer.	17	20	24
Chinese	27	26	49
Latina	14	9	31
Vietnamese	19	22	38
White	28	29	25

We cross-tabulated these data from the callback interviews with the information on income that these respondents provided in the Pathways survey. Results revealed that Chinese and whites who had higher incomes and were above the poverty line were more likely than those with low incomes to find the income questions difficult. The reverse situation was found for Latinas and Vietnamese: those with lower incomes and who were below the poverty line were most likely to consider the income questions difficult.

The African American data were not easy to interpret. Respondents reporting annual family incomes less than $20,000 were more likely to find the income questions difficult than those with higher incomes (13% v 5%). On the other hand, African Americans below the poverty line were less likely to find the income questions difficult than those above the poverty line (4% v 19%). These puzzling results may be a function of the income cut-point used in these analyses.

In the callback interviews, respondents also were asked how likely most people would be to answer questions about income truthfully. Compared to 14% of whites, over 20% of the African Americans and Chinese and about one-third of the Latinas and Vietnamese thought that most people were not very or not at all likely to be truthful. Notably, one-third of the Vietnamese respondents called back chose not to answer this question.

Table 4 shows the distribution of respondents who thought people would not answer income questions truthfully by income reported in the Pathways survey. Although the proportion of African Americans, Chinese, and whites who felt people would be untruthful did not vary by income, most persons in these groups who said they thought people would be untruthful reported incomes above the poverty line. These data coincide particularly with qualitative data we later obtained from focus groups indicating that African Americans may be embarrassed to admit low incomes.

In contrast, most of the Latinas and Vietnamese who said that people would be untruthful in reporting income themselves reported low incomes and poverty status. Qualitative data revealed that concerns about immigration status and eligibility for welfare benefits may motivate under-reporting of income by these groups. Such analyses can help to estimate the direction of bias in problematic data; however, we have not yet resolved ethical issues raised by our findings.

Table 4. Percentage Not Likely to Answer Questions on Income Truthfully by Reported Income and Poverty Status

	< $20K	≥ $20K	Below Poverty	Above Poverty
African-Amer.	7	8	1	17
Chinese	10	10	2	19
Latina	17	4	18	9
Vietnamese	26	3	19	11
White	4	4	3	8

Further analysis of the callback data promises to reveal more about the validity, reliability, and comparability of responses to the income questions. We have found, for example, that answering questions about income truthfully does not appear to be related to the language of the interview.

Reliability of Data on Income

As we uncovered problems with Pathways survey data on income, concern mounted about implications for data analysis in the Pathways program project. Should data on annual family income and poverty status be ignored in analysis or can these variables contribute to understanding issues in utilization of cancer screening by the five ethnic groups?

To investigate this issue, we checked the reliability of data on income and poverty status through a series of cross-tabulations and correlations. As Table 5 illustrates, respondents with annual family incomes under $20,000 were much more likely to be below the poverty level than were those with higher incomes. This result provides some evidence of data reliability.

Again qualitative data combined with additional quantitative analysis helped to explain between-group differences observed: due in part to larger household sizes, Hispanics and Vietnamese were much more likely to have incomes below the poverty level than were African

Americans, Chinese, and particularly, whites.

Table 5. Percentage Below the Poverty Level by Annual Family Income

	< $20K	≥ $20K
African-Amer.	33	3
Chinese	37	5
Latina	71	13
Vietnamese	74	18
White	21	3

Comparing the percent of respondents reporting that they had private health insurance by reported annual family income provided additional evidence that the latter variable is reliable. Table 6 shows that in all groups, respondents with a yearly family income of $20,000 or more were much more likely to have private health insurance than were respondents with lower family incomes. However, large disparities were observed in the proportion of each racial/ethnic group with private health insurance. Most Chinese and whites had private insurance even if their family incomes were less than $20,000 per year. In contrast, only one-third of higher income Vietnamese had private insurance.

Table 6. Percentage with Private Health Insurance by Annual Family Income

	< $20K	≥ $20K
African-Amer.	35	91
Chinese	66	91
Latina	23	79
Vietnamese	7	35
White	54	85

We corroborated these findings by conducting similar analyses with data from BACCIS and the VPS. In the BACCIS data, for example, income treated as a continuous variable was strongly and significantly correlated with having private health insurance in each racial/ethnic group. Table 7 shows that these correlations were significantly larger for African Americans and Chinese than for whites, but all correlations were in the same direction.

Table 7. BACCIS: Correlation of Income with Private Health Insurance

	r	p
African-Amer.	0.481	0.001
Chinese	0.519	0.001
Other Asian	0.508	0.001
Latina	0.398	0.001
White	0.369	0.001

Similarly, as shown in Table 8, correlations between reported income and education were significant and strong within each of the groups surveyed by BACCIS. These results provide further evidence that, despite its problems, income is a reasonably reliable variable.

This does not mean, of course, that we should ignore the issues discovered. We conclude from our qualitative and quantitative data analyses that (1) reasons for inquiring about income should be clearly explained, (2) alternative ways to collect income data should be tested, (3) a specific code for missing data should be included in data sets, and (4) the reliability of income data should be checked through respondent callbacks, as well as through cross-tabulations and correlations with other related variables. Finally, (5) throughout data analysis it is important to be aware of possible biases and not to assume that data on income are automatically valid, reliable, and comparable across racial/ethnic groups.

Table 8. BACCIS: Correlation of Income with Education

	r	p
African-Amer.	0.31	0.001
Chinese	0.459	0.001
Other Asian	0.336	0.001
Latina	0.372	0.001
White	0.417	0.001

Other Illustrations

Other data illustrate two additional ways in which we have combined qualitative and quantitative analysis to examine the validity, reliability, and comparability of data gathered from multi-ethnic populations in health surveys.

Conducting factor analyses by racial/ethnic group can be a useful technique. We did this in the BACCIS data for eight items concerning barriers to medical care. Three factors emerged for all racial/ethnic groups, and seven items loaded in the same way on these factors within each group. However, one question, "How often do you feel your doctor or nurse understands your concerns about health?", loaded on Factor 3 for Chinese, but on Factor 1 for other groups. Our qualitative data revealed that Chinese translators considered this item one of the most difficult to express in Mandarin and Cantonese. We dropped the item and improved the reliability of the resulting scales across all racial/ethnic groups.

Table 9 shows the Cronbach alphas for the three factors after the troublesome question was removed. The communication factor is very reliable with alpha near .8 for all racial/ethnic groups. The financial factor is also very solid. However, the availability factor is less reliable, especially for African Americans, and must be viewed with caution. Our next step will be to correlate each of these factors with variables related to factor content.

Table 9. BACCIS: Barriers to Medical Care, Cronbach's Alpha for Three Factors

	Communication	Financial	Availability
African-Amer.	0.78	0.80	0.36
Chinese	0.79	0.78	0.48
Latina	0.80	0.89	0.62
White	0.78	0.89	0.53
Total	0.79	0.84	0.51

Another technique is to compare reliabilities by racial/ethnic group. Table 10 shows the percentage of responses to three questions from callback interviews that agreed with the responses given at the time of the Pathways survey. Agreement was high on the

question, "Have you ever had a mammogram?" This is a factual question about a clearly defined event that can be answered simply by saying "yes" or "no".

The other two questions had numeric responses and showed significant differences among groups when exact concordance was required. Using other measures, "times you saw a doctor in the past year" still showed significant variation between groups, but "years in the U.S." showed generally good agreement and groups did not significantly differ from each other. Our qualitative data revealed that people have difficulty remembering the number of times they saw the doctor in the past year. The year of immigration is memorable, but calculating total years in the U.S. can be challenging during an interview and errors apparently are made.

Table 10. Percent Agreement between Pathways Survey and Callbacks on Three Questions

	Ever Had Mammogram	Times Saw M.D.	Years in U.S.
African-Amer.	96	40	
Chinese	95	33	82
Latina	95	50	78
Vietnamese	89	27	51
White	97	42	

Summary

In summary, the validity, reliability, and comparability of health survey data collected from multi-ethnic, multi-lingual populations should not be taken for granted.

Some qualitative methods that investigators can easily use to check the quality of their data are:

- Carefully examine pretest results. In the rush to get surveys into the field, pretest findings are often used only to revise questions and then forgotten.
- Ask investigators, translators, and survey workers to rate and comment on questions.
- Debrief survey workers. After completing data collection, interviewers have a wealth of information about which questions do and do not work well and why.

Other qualitative methods used in our NCHS investigation include focus groups[2] and think aloud interviews[3] conducted with low-income women from the five racial/ethnic groups in their native language. We also tracked the evolution of questions in the Pathways survey instrument, keeping notes about the reasons draft items were modified or discarded. Later we interviewed Pathways core investigators from the relevant racial/ethnic groups to verify and discuss the cultural, linguistic, or other issues that affected their shaping of survey questions. Such techniques have not been discussed in this paper because they require time and resources generally unavailable to health survey researchers.

Quantitative methods that are readily applied include checking missing data rates and analyzing data by race/ethnicity, as well as by language of interview, country of birth and other variables such as age and education that may affect sub-group responses.

Quantitative methods that require additional time and resources include callbacks to a random sample of survey respondents to check the reliability of responses to particular questions and to obtain data on attitudes toward troublesome survey items. Comparing alternative forms of questions to gather data on the same variable is also a valuable technique.

While both qualitative and quantitative methods used independently can provide important insight into the quality of health survey data, we have found that these approaches complement each other in (1) identifying troublesome variables; (2) checking the validity, reliability, and comparability of data across racial/ethnic groups; and (3) pinpointing particular methodological problems. Combining qualitative and quantitative approaches also (4) increases sensitivity to potential bias in the data. And both approaches have important contributions to make in (5) identifying and testing better survey questions and data collection methods.

We find this work exciting and encourage others who conduct qualitative and quantitative analyses such as we have described today to disseminate their results to the research community. To improve the validity, reliability, and comparability of health data obtained from multi-ethnic populations, results of methodological studies conducted with different populations and in different regions of the country also need to be shared and compared.

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LINKING DATA SETS FOR STUDY OF TREATMENT VARIATION AMONG MINORITY POPULATIONS

Selma C. Kunitz, KAI; Matthew Jaro, MatchWare; Gene Therriault, NY State Department of Public Health; Rene Kozloff, KAI; Harvey Schwartz, AHCPR

The primary objectives of this record linkage methodology project sponsored by AHCPR through contract 282-94-2005 are to:1) link two patient level related data sets that contain racial and ethnic descriptors; and 2) assess the value of the linked data to address medical effectiveness research questions that focus on the quality, effectiveness, and outcomes from care for minority populations. Activities include:

- **Identification** of suitable health related data sets;
- **Linkage** of these data sets;
- **Assessment** of the quality and utility of the data with respect to addressing health services research on minority populations;
- **Creation** of a user-friendly manual that provides a step-by-step approach to linkage methodology for use by researchers; and
- **Documentation** of the project through a report that describes the data accuracy and reliability, problems and their resolution, project steps, and recommendations for future related endeavors.

The linkage software used for this project is MatchWare Technology Incorporated's (MTI) **AUTOMATCH**. It is generalized to be consistent with good statistical practice. Data management, clerical review, linked record extraction, unduplication, blocking, multi-pass matching and frequency analysis are all provided in both personal computer and mainframe environments. It is a robust system with the following features:

- **PC file size limitations** - to avoid problems associated with storing multiple copies of large data files, or the slow speed associated with relational data base management systems, the record linkage software provides blocking by an indexing system rather than sorting. Multiple-pass matching is handled through the creation of residual pointer files keep track of records matched on previous passes.
- **Questionable links** - to handle uncertain matches, an individual reviews the linked pairs to establish decision cut-off thresholds. The clerical review system maintains a history file so that the same records do not have to be continually reexamined if the matcher is re-run.
- **Duplicate records** - all duplicate records are identified on all files through a report generator and file extraction program.

Selection of Data Sets

We received approval from the State of New York to utilize the Statewide Planning and Research Cooperative System (SPARCS) files which contain all acute hospital discharge and claims data, the SPARCS ambulatory surgical files, and the Cardiac Surgery Reporting System (CSRS) files which are a research data set. Since the project was initiated in 1994, we requested files for the 1991, 1992, and 1993 time periods. Figure 1 summarizes the size of the original data files.

While the discharge and claims files have been discrete files, the State of New York will combine the data beginning in 1995 and thus, provided them in a combined format. The ambulatory surgery files were not segregated by year and contain slightly more than two million records. The CSRS data files are also summarized by year and contain a considerably smaller number of records because of the focus of the records. Hannan *et al*, 1990; Hannan *et al*, 1992 articles describe the utility of these data for medical effectiveness studies.

OBTAINING THE DATA

The process of obtaining data sets always takes longer than anticipated. We began the request for the data sets in June, 1994 and received one set in January, 1995 and another set in April, 1995. Some of the issues we confronted in the data acquisition process are as follows:

- **Identifying Responsible Source** - identifying the responsible person for the SPARCS data sets which are administrative data sets was not an issue. However, identifying the responsible person for the CSRS research data sets was a time consuming task. It took approximately two months to

identify the person responsible for approving data set use and almost daily telephone calls to ensure that we actually received the data.

- **Field Size Differences** - The MRN in the SPARCS DDA/UBF file is 10 characters and was encrypted as such. However, the MRN in the Ambulatory Surgery file is defined as 17 characters (the first 10 characters actually contained the MRN, the last seven characters were spaces.) When an initial match was attempted between the DDA/UBF and the Ambulatory Surgery files, not one set of records matched. The problem was resolved by recreating the Ambulatory Surgery File using only the first 10 characters of the MRN.

- **Documentation** - although each of the data sets was accompanied by documentation, it was not always current and did not reflect the actual contents of the data sets.

RESEARCH QUESTION

To focus the project a suitable research question was identified that relates risk factors, treatment and outcome of cardiovascular disease to minority status as follows:

Are the racial/ethnic differences in mortality and morbidity from coronary heart disease related to racial and ethnic differences in treatment?

The working *hypothesis* is that minorities are less likely to receive surgical treatment for coronary artery disease and therefore as a group, experience higher incidence of cardiovascular morbidity and mortality than the majority U.S. population. The original research plan suggested the use of ICD-9 codes 410 - 414. The low yield on initial matches, however, indicated that we needed to expand these codes to obtain a more complete match between the SPARCS and CSRS files. The range was subsequently expanded to all diseases of the circulatory system (390xx-459xx) and increased the number of potential subjects as shown in Figure 2.

DATA PREPARATION

Encryption - MRN, Admission numbers, and Physician License numbers were encrypted to ensure privacy. They were encrypted using the same rules across all files to allow matching and longitudinal analysis. However, the encryption process does degrade the efficiency of the matching software. The matching software used in this study can take into account slight differences between identifiers such as transposition of characters and adjust the match for them. For example, if MRNs were off by one number because of a typographical error and all the rest of the information on the records used in the match was the same, the software would treat this as a typographical error and consider the records to be matches. However, the encryption process takes two MRNs with transposed numbers and converts them to two totally different numbers. Therefore, the software benefits in this area are lost.

Data Conversion for Linkage - The *Automatch* record linkage system for this project was implemented on a high-performance personal computer. The system accepts patient level data as *DOS* files consisting of fixed length records with *ASCII* characters. Cases and variables required for linkage were selected and converted to this format by project staff using *SAS* and *C* data manipulation programs developed on NIH and internal computer systems for these purposes. In an effort to reduce the potential for false matches, as well as minimize required disk storage space and linkage processing times, only those cases and variables that were expected to participate directly in the linkage process were included. For ambulatory surgery and inpatient records, only cases with cardiac related diagnoses were included.

Cardiac related diagnoses were defined as any diagnosis (admitting, principal, or any other) of ischemic heart disease (ICD-9 code in the expanded range.

Person and Event Identifiers. The goal of the linkage process is a longitudinal treatment history for persons with cardiac related diagnoses. Person and event identifiers that appear to be common across two or more of the original data sources, or across two or more events within the same data system, were identified from source data descriptions. Data coding differences prevented direct use of some of the original data values. Instead, all common data items were converted to standardized values.

As mentioned above, the SPARCS records for this project were created by the NY DOH through deterministic matching of Discharge Data Abstract, (DDA) and Uniform Billing Form (UBF)

data. Hospital ID, patient medical record number, patient admission number, and other identifying variables were used by NY DOH staff to link separately reported DDA and UBF records. Typical final linkage rates over the study period were near 95%. That is, approximately 5% of reported discharge records had no matching billing record. In addition, approximately 5% of reported billing records had no matching discharge record. We did not attempt to link any residual records using probabilistic linkage methods.

Person and Event Identifiers - SPARCS variables that provided descriptive information about a cardiac patient or a cardiac related hospitalization were selected and prepared for grouping and matching purposes. Because SPARCS records were created by linking separate DDA and UBF records, the records contained data from both of these medical data sources and both were used for matching.

A measure of SPARCS data reliability was obtained by comparing values of person and event identifiers that were common to both DDA and UBF. Comparisons, the results of which are shown in Figure 3, were made only if neither value was missing. It is likely that the high number of errors for admission number, medical record number, and physician were caused by the encryption process. For example, all of the physician license numbers noted as errors had a value of *00120012*, which may be the encrypted version of *00000000*.

The matching process was initiated with the SPARKS and ambulatory surgery files and results are shown in Figure 4. There are several items of interest in this figure. Physician discordance is very high (72%), perhaps because admitting physician is used on one file while surgeon is used on the other. "Unexpected agreements" indicate individuals who had ambulatory surgery and were then admitted to the hospital, perhaps because of complications. Figure 5 illustrates the matching process between the CSRS files and UBF/DDA files for 1993. The numbers are consistent across years. The higher the weight the greater the credibility of the match and thus, 97% of the matches weights greater than 20 indicate "good" matches. Figure 6 shows the match and error counts for 4 and 6 passes that were performed to obtain matches for the 1993 data. In the 85% (6 passes) of the 22,492 CSRS records that were matched with the UBF/DDA files, over 79% of the matched records had 1, 2, or 3 disagreements among fields. As shown in Figure 7, MRN, attending physician, and procedure had high degrees of discordance, perhaps because admitting number is sometimes used in place of MRN, because attending and operating physician are often interchanged on the these files, and because a procedure may be listed as primary on one file but not on the other because of reimbursement policies.

Since a primary research interest for this project is the difference in treatment across racial and ethnic subgroups, consistency of these field prior to matching and between matched and unmatched records is important. Figures 8, 9, and 10 illustrate the consistency of percentages of racial and ethnic minority patients in the CSRS and UBF/DDF files pre and post matching as well as the proportion of matched and unmatched records.

These initial results show that the initial purposes for which data are collected affects the utility for linkage. For example, the UBF files, which are used for billing, are more likely to have accurate admitting and discharge dates, while the DDA or discharge abstracts are more likely to have more accurate attending physicians. Likewise, the CSRS files are more likely to have accurate clinical data. The linkage methods, which emanate from the census environment, must be adapted to the idiosyncracies of health related data sets and thus, the purpose for which data are collected are very important. Linkage across health related data sets will enhance the value of the data sets and health related research will be aided with application of linkage methods.

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FIGURE 1: PROJECT DATA FILES

DATA SET	YEAR	RECORDS
SPARCS COMBINED DDF/UBF FILES	1991	1,687,521
	1992	1,677,948
	1993	1,660,109
AMBULATORY SURGERY FILE	1991 - 1993	2,121,542
CARDIAC SURGERY REPORTING SYSTEM (CSRS)	1991	19,783
	1992	21,592
	1993	22,491

FIGURE 2: UNIVERSE OF SUBJECTS

DATA SET	YEAR	ICD-9 410 - 414	ICD-9 390 - 459
SPARCS	1991	170,779	626,222
	1992	189,198	699,246
	1993	190,497	714,583

FIGURE 3: DISCREPENCIES ON UBF/DDA MATCHED FILE

YEAR	1992		1993	
	N	%	N	%
FIELD NAME	699,246		714,583	
ADMIT NUMBER	125,473	18%	86,855	12%
MRN	50,107	7%	34,808	5%
PRINCIPAL PROCEDURE	1,992	<1%	1,777	<1%
PACE MAKERS	2,318	<1%	2,183	<1%
PHYSICIAN	144,597	21%	155,125	22%
GENDER	655	<1%	673	<1%
BIRTH DATE	5,583	<1%	5,707	1%
COUNTY CODE	6,490	1%	5,052	1%
ZIP CODE	9,256	1%	6,463	1%

FIGURE 4: INITIAL MATCH AND DISCORDANCE - UBF/DDA WITH AMBULATORY SURGERY FILE (1991 - 1993)

	DISCORDANCE	
	N	%
TOTAL N (AMBULATORY SURGERY)	2,121,542	
MATCHED PAIRS	31,597	1%
FIELD		
HOSPITAL CODE	350	1%
MRN	1,549	5%
PHYSICIAN	22,619	72%
GENDER	293	1%
BIRTH DATE	386	1%
ZIP CODE	1,218	4%
COUNTY	1,150	4%
STATE	119	<1%
UNEXPECTED AGREEMENTS		
ADMIT NUMBER	2,661	8%
ADMIT DATE	1,728	6%
PROCEDURE DATE	1,079	3%
OVERNIGHT	361	1%

FIGURE 5: INITIAL MATCHES AND DISCORDANCE
UBF/DDA WITH CSRS - 1993 FILES
WEIGHTS

	(4 PASSES)		(6 PASSES)	
ERRORS	N	%	N	%
MATCHES	22,491		22,491	
WEIGHTS	18,612	86%	19,217	89%
71 - 60	4	<0%	4	<0%
40 - 59	8,129	44%	8,129	42%
20 - 39	9,893	53%	10,336	54%
10 - 19	497	3%	612	3%
0 - 9	81	<1%	127	<0%

FIGURE 6: INITIAL MATCHES AND DISCORDANCE UBF/DDA WITH CSRS
1993 FILES - ERROR COUNTS

	PAIRS (4 PASSES)			MATCHES (6 PASSES)		
ERRORS	N	%	AVG.WGT.	N	%	AVG. WGT.
	22,491			22,491		
MATCHES	18,612	83%		19,217	85%	
ERRORS						
0	1,482	8%	40.8	1,482	8%	40.8
1	6,614	35.5%	40.1	6,616	34%	40.1
2	5,575	30%	37.2	5,585	29%	37.2
3	2,979	16%	34.3	3,022	16%	34.0
4	1,245	6.7%	30.0	1,277	7%	29.7
5 - 9	717	3.9%	25.7- 5.0	1,185	6%	25.4-14.5
10 - 15	-	-	-	50	.2%	11.8- 1.0

FIGURE 7: INITIAL MATCHES AND DISCORDANCE
UBF/DDA WITH CSRS - 1993 FILES - DEMOGRAPHICS

	MATCHES (4 PASSES)		MATCHES (6 PASSES)	
RESULTS	N	%	N	%
CSRS SIZE	22,491		22,491	
MATCHES	18,612	83%	19,217	85%
DISCORDANCE				
GENDER	231	1.2%	248	1.3%
BIRTH DATE	587	3.2%	646	3.4%
COUNTY CODE	1,376	7.4%	1,481	7.7%
STATE	277	1.5%	289	1.5%
ETHNICITY	615	3.3%	641	3.3%
RACE	2,375	12.8%	2,483	12.9%
AGE ON JANUARY 1	704	3.8%	757	3.9%

FIGURE 8: RACE ACROSS SUBSETS PRIOR TO MATCHING

SUBSET AND RACE	1991		1992		1993	
	N	%	N	%	N	%
DDA/UBF	626,222		699,246		714,583	
BLACK	83,111	13%	95,657	14%	100,304	14%
WHITE	481,170	77%	538,447	77%	545,140	76%
OTHER	61,941	10%	65,142	9%	69,139	10%
CSRS	19,783		21,592		22,491	
BLACK	908	5%	1,056	5%	1,170	5%
WHITE	18,217	92%	19,854	92%	20,437	91%
OTHER	649	3%	680	3%	878	4%
MISSING	9	<1%	2	<1%	6	<1%

FIGURE 9: ETHNICITY - MATCHED AND UNMATCHED RECORDS FOR CSRS

ETHNICITY	1991		1992		1993	
	N	%	N	%	N	%
MATCHED	16,777		18,021		19,527	
HISPANIC	758	5%	830	5%	924	5%
OTHER	16,019	95%	17,188	95%	18,287	95%
MISSING	6	<1%	3	<1%	6	<1%
UNMATCHED	3,006		3,570		3,273	
HISPANIC	141	5%	171	5%	134	4%
OTHER	2,865	95%	3,398	95%	3,138	96%
MISSING	3	<1%	1	<1%	1	<1%

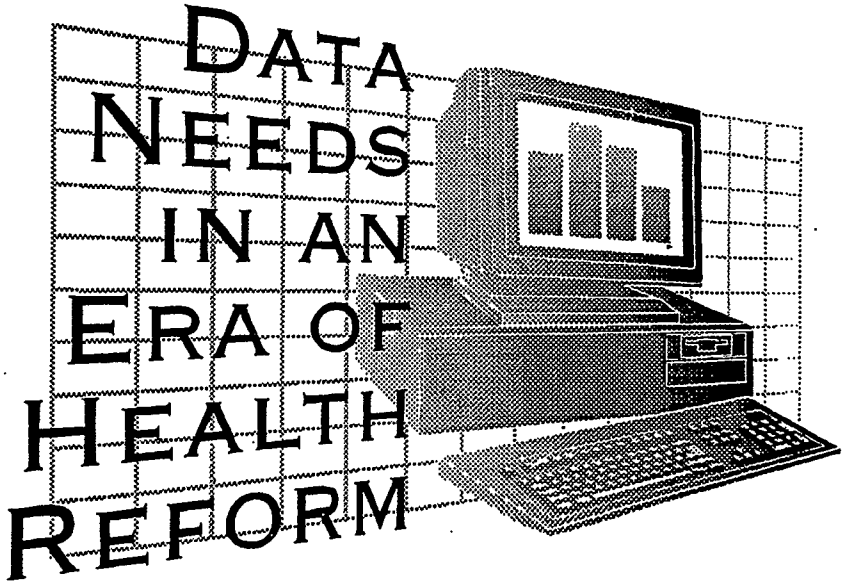
FIGURE 10: RACE - MATCHED AND UNMATCHED RECORDS FOR CSRS

RACE	1991		1992		1993	
	N	%	N	%	N	%
MATCHED	16,777		18,021		19,527	
BLACK	767	5%	902	5%	1,023	5%
WHITE	15,475	92%	16,559	92%	17,428	91%
OTHER	529	3%	559	3%	760	4%
MISSING	6	<1%	1	<1%	6	<1%
UNMATCHED	3,006		3,570		3,273	
BLACK	141	5%	154	4%	147	4%
WHITE	2,742	91%	3,294	92%	3,008	92%
OTHER	120	4%	121	3%	118	4%
MISSING	3	<1%	1	<1%	1	<1%

Sixth through Eight Plenary Sessions

National Committee on Vital and Health Statistics

45th Anniversary Symposium



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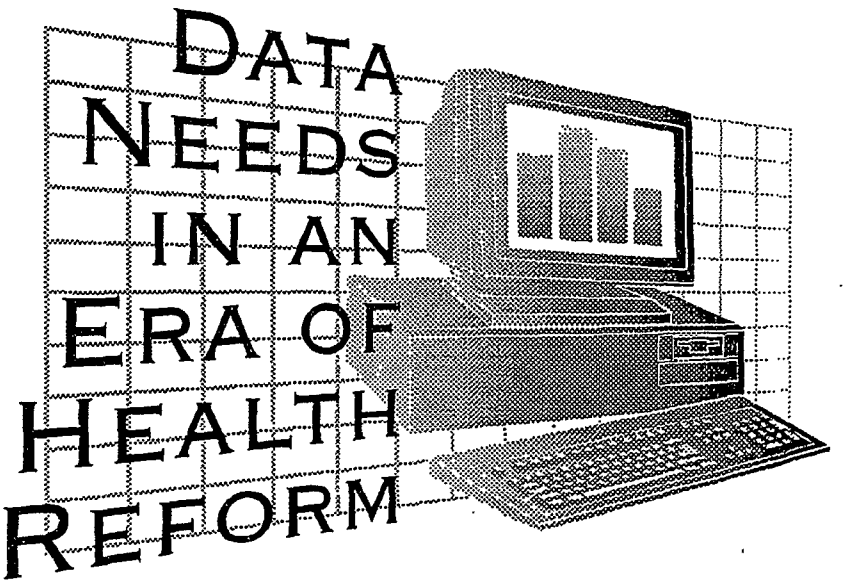
Sixth through Eighth Plenary Sessions

This portion of the program, together with the Third though Fifth Plenary Sessions, will be printed under separate cover. All conference participants will receive a copy.

Appendix



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Division of Health Interview Statistics

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Associate Professor of Psychiatry
University of Maryland at Baltimore
School of Medicine
645 West Redwood Street, IPHB
Baltimore, Maryland 21201

George H. Van Amburg, M.P.H. (V)
State Registrar and Chief
Center for Health Statistics
Michigan Department of Public Health
4323 North Logan Street, P.O. Box 30195
Ann Arbor, Michigan 48909

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**National Center for Health Statistics
6525 Belcrest Road
Hyattsville, Maryland 20782

PROGRAM SESSION CHAIRPERSONS

Catharine W. Burt, Ed.D.** (G)
Chief, Ambulatory Statistics Branch
Division of Health Care Statistics

Richard G. Cornell, M.S., Ph.D.
(First Plenary)
Professor of Biostatistics and
Interim Dean, School of Public Health
University of Michigan
109 South Observatory Street
Ann Arbor, Michigan 48109-2029

Charles Croner, Ph.D.** (F)
Statistical Geographer
Office of Research and Methodology

Lester R. Curtin, Ph.D.** (B)
Chief, Statistical Methods Staff
Office of Research and Methodology

Lois A. Fingerhut, M.A.** (A)
Special Assistant for Injury Epidemiology
Office of Analysis, Epidemiology, and
Health Promotion

Wilbur C. Hadden, M.A.** (S)
Statistician, Division of Health
Examination Statistics

Robert B. Hartford, Ph.D.** (E)
Acting Director
Office of International Statistics

Gerry E. Hendershot, Ph.D.** (N)
Deputy Director for Science
Division of Health Interview Statistics

Lisa I. Iezzoni, M.D., M.Sc. (X)
Co-Director of Research
Division of General Medicine and
Primary Care, Beth Israel Hospital
Harvard Medical School
330 Brookline Avenue, Room LY326
Boston, Massachusetts 02215

Judith Miller Jones (Third-Ninth Plenarys)
Director
The National Health Policy Forum
2021 K Street, N.W., Suite 800
Washington, D.C. 20006

John L. Kiely, Ph.D.** (I)
Chief, Infant and Child Health
Studies Branch
Office of Analysis, Epidemiology,
and Health Promotion

Felicia B. LeClere, Ph.D.** (L)
Health Statistician
Division of Health Interview Statistics

Diane M. Makuc, Dr.P.H.** (T)
Chief, Analytic Studies Branch
Division of Health and Utilization Analysis

Paul W. Newacheck, Dr.P.H. (M)
Professor of Health Policy and Pediatrics
Institute for Health Policy Studies
University of California at San Francisco
1388 Sutter Street, 11th Floor
San Francisco, California 94109

Elsie R. Pamuk, Ph.D.** (O)
Health Statistician
Office of Analysis and Epidemiology

Gregory R. Pappas, M.D., Ph.D.** (K)
Special Assistant to the Director
Office of Planning and Extramural Programs

P. Ellen Parsons, Ph.D., M.P.H.**
(Second Plenary and P)
Survey Statistician
Division of Health Interview Statistics

Susan M. Schappert, M.A.** (C)
Survey Statistician
Division of Health Care Statistics

Susan E. Schober, Ph.D.** (Q)
Epidemiologist
Division of Health Promotion

Bruce Steinwald (U-Substitute)
Vice President
Health Technology Associates
Suite 200 East
1100 New York Avenue, N.W.
Washington, D.C. 20005

James W. Thompson, M.D. (W)
Associate Professor of Psychiatry
University of Maryland at Baltimore
School of Medicine
645 West Redwood Street, IPHB
Baltimore, Maryland 21201

George H. Van Amburg, M.P.H. (V)
State Registrar and Chief
Center for Health Statistics
Michigan Department of Public Health
3423 North Martin Luther King Boulevard
Lansing, Michigan 48906

Joan F. Van Nostrand, D.P.A.** (J)
Coordinator of Data on Aging
Office of Vital and Health Statistics
Systems

Diane K. Wagener, Ph.D.** (H)
Special Assistant
Environmental Epidemiology
Office of Analysis, Epidemiology,
and Health Promotion

Ronald W. Wilson, M.A.** (R)
NCHS AIDS Liaison

( ) Indicates session.

Elizabeth R. Zell, M.Stat. (D)
Chief, Assessment Branch
Data Management Division
National Immunization Program
Centers for Disease Control and Prevention
Corporate Square Boulevard
Atlanta, Georgia 30329

**National Center for Health Statistics
6525 Belcrest Road
Hyattsville, Maryland 20782

Lu Ann Aday, Ph.D. (Second Plenary)
Professor of Behavioral Sciences
University of Texas
School of Public Health
P.O. Box 20186, RAS East 311
Houston, Texas 77225

Dawn K. Aldridge, M.S. (T)
Research Associate, Comprehensive Perinatal Outreach Program
Los Angeles County Department of Health Services
500 Shatto Place, Suite 425
Los Angeles, California 90020

Jack Anderson** (Opening Ceremony)
Acting Director

Dennis Andrulis, Ph.D. (K)
President, National Public Health and Hospital Institute
1212 New York Avenue, NW, Suite 800
Washington, D.C. 20005

Jennifer J. Balogh, M.S.W., M.P.H. (A)
Coordinator, Injury Surveillance Systems Prevention Program
Contra Costa Health Services Department
75 Santa Barbara Road
Pleasant Hill, California 94523-4200

Cibele Barbosa, M.D., M.P.H. (R)
Medical Epidemiologist
Division of HIV Prevention
Council of State and Territorial Epidemiologists, CDC
1600 Clifton Road, NE, Mail Stop E-46
Atlanta, Georgia 30333

Doris Bardehle, Dr.Sc.Med. (H)
Head, Department of Health Statistics
Office of the Ministry of Labour, Health, and Social Affairs
Postfach 201012
Bielefeld 33548, Germany

Elizabeth Barnett, Ph.D. (S)
Assistant Professor, Center for Health Promotion and Disease Prevention
West Virginia University
Box 9005
Morgantown, West Virginia 26506-9005

David Drake Barney, B.S., M.S.W. (R)
Research and Evaluation Specialist
National Native American AIDS Prevention Center
5350 South Western, Suite 500
Oklahoma City, Oklahoma 73109

Dawn M. Berney, M.P.A. (A)
Research Associate, Philadelphia Health Management Association
260 South Broad Street
Philadelphia, Pennsylvania 19102

Nancy Breen, Ph.D. (S)
Economist, Applied Research Branch
National Cancer Institute, NIH
713 Ivy League Lane
Rockville, Maryland 20850-1872

E. Richard Brown, Ph.D. (Second Plenary)
Director
Center for Health Policy Research
University of California at Los Angeles
10833 LeConte Avenue
Los Angeles, California 90024

Jay S. Buechner, Ph.D. (T)
Chief, Office of Health Statistics
Rhode Island Department of Health
3 Capitol Hill
Providence, Rhode Island 02908

John Charlton, M.Sc., D.I.C. (B)
Statistician, Office of Population Censuses and Surveys
St. Catherine's House
10 Kingsway
London WC2B 6JP, England

Frances M. Chevarley, Ph.D.** (N)
Biostatistician
Division of Health Interview Statistics

Michelle Chino, M.S. (B)
Programs Specialist
Albuquerque Area Indian Health Board
301 Gold Avenue, SW, Suite 105
Albuquerque, New Mexico 87102

Chiquita A. Collins, M.A. (S)
Research Assistant
Department of Sociology
Institute for Social Research
University of Michigan
P.O. Box 1248
Ann Arbor, Michigan 48106-1248

Michael Cooperstock, M.D., M.P.H. (S)
Associate Professor of Child Health
University of Missouri
School of Medicine
One Hospital Drive
Columbia, Missouri 65212

Lori Cornelius-Quast, R.N. (C)
Measurement Evaluator
Health Sciences Research Section
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Ellen K. Cromley, Ph.D. (F)
Associate Professor
Department of Geography
University of Connecticut
354 Mansfield Road, Room 438
Box U-148
Storrs, Connecticut 06269-2148

( ) Indicates session.

Carol N. D'Onofrio, Dr.P.H. (X)
Research Scientist
Northern California Cancer Center
32960 Alvarado-Niles Road, Suite 600
P.O. Box 5033
Union City, California 94587

Charles H. Darby, M.S. (Q)
Master Statistician, Health Services Evaluation
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Larry Deutsch, M.D., M.P.H. (V)
Project Director
Children's Health Network
Hartford Primary Care Consortium, Inc.
30 Arbor Street, North
Hartford, Connecticut 06106

Anne Dievler, Ph.D. (K)
Health Policy Consultant
2204 Colston Drive, #202
Silver Spring, Maryland 20910

Carolyn DiGuiseppi, M.D., M.P.H. (Q)
Senior Health Policy Analyst, The Forum for Quality/Effectiveness in Hlth Care
Agency for Health Care Policy/Research
6000 Executive Boulevard, Suite 310
Rockville, Maryland 20852

William F. Eddy, Ph.D. (First Plenary)
Professor, Department of Statistics
Carnegie Mellon University
5000 Forbes Avenue
Pittsburgh, Pennsylvania 15212-3890

Jeffrey Todd Eickholt, B.S. (M)
Data Analyst, Section of Biostatistics
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Donna L. Eisenhower, Ph.D. (O)
Senior Survey Researcher
Mathematica Policy Research, Inc.
Box 2393
Plainsboro, New Jersey 08540

Anne Elixhauser, Ph.D. (U)
Service Fellow
Division of Provider Studies
Center for Intramural Research
Agency for Health Care Policy/Research
2101 East Jefferson, Suite 500
Rockville, Maryland 20852

Beth Erickson, M.S. (U)
Project Manager
Light Industries
8223 Cloverleaf Drive, Suite 100
Millersville, Maryland 21108

Mary K. Ethen, M.P.H. (X)
Research Specialist
Bureau of Vital Statistics
Texas Department of Health
1100 West 49th Street
Austin, Texas 78756-3191

Janis A. Barry Figueroa, Ph.D. (L)
Associate Professor of Economics
Division of the Social Sciences
Fordham University
113 West 60th Street
New York, New York 10023

Maryanne J. Florio, M.Ed. (I)
Research Scientist
Maternal and Child Health Epidemiology and Program Development
New Jersey Department of Health
50 East State Street, CN 364
Trenton, New Jersey 08625

Emma L. Frazier, Ph.D. (T)
Chief, Data Management Section
Center for Chronic Disease Prevention and Health Promotion, CDC
4770 Buford Highway, NE
Atlanta, Georgia 30341-3724

Lynne Fullerton, M.A. (O)
Research Specialist
Department of Emergency Medicine
University of New Mexico School of Medicine
Ambulatory Care Center, 4W
Albuquerque, New Mexico 87131-5246

Robert E. Fullilove, Ed.D. (K)
Associate Dean for Community and Minority Affairs
Columbia University School of Public Health
600 West 168th Street
New York, New York 10032

Adele D. Furrie, B.A. (N)
Director, Post-Censal Surveys Program
Statistics Canada
Jean Talon Building, 9C-8
Tunneys Pasture
Ottawa K1A 0T6, Canada

Norma I. Gavin, Ph.D. (D)
Senior Health Policy Analyst
Social and Health Policy Center
Research Triangle Institute
1615 M Street, NW, Suite 740
Washington, D.C. 20036-3209

David James Gemmel, M.A. (L)
Director, Department of Research
Western Reserve Care System
345 Oak Hill
Youngstown, Ohio 44501

Marsha R. Gold, Sc.D. (P)
Senior Fellow
Mathematica Policy Research, Inc.
600 Maryland Avenue, SW, Suite 550
Washington, D.C. 20024-2512

Elicia J. Herz, Ph.D. (Q)
Project Manager
The MEDSTAT Group
4401 Connecticut Ave., NW, Suite 400
Washington, D.C. 20008

Anna Regula Herzog, Ph.D. (J)
Research Scientist
Institute for Social Research
The University of Michigan
P.O. Box 1248
Ann Arbor, Michigan 48106-1248

Denise M. Hynes, R.N., M.P.H., Ph.D. (H)
Senior Health Scientist, Midwest Center for Health Services/Policy Research
Edward Hines, Jr. VA Hospital
P.O. Box 5000, Room B255 (151H)
Hines, Illinois 60141

Debbie S. Indyk, Ph.D. (W)
Assistant Professor
Department of Community Medicine
Mount Sinai Medical Center
One Gustave Levy Place, Box 1045
New York, New York 10029

Mary E. Jackson, Ph.D. (J)
Project Manager
Policy and Research Division
The MEDSTAT Group
125 Cambridge Park Drive
Cambridge, Massachusetts 02140

Jeannette Jackson-Thompson, Ph.D. (P)
Director, Behavioral Risk Factor Surveillance System Project
Missouri Department of Health
101 Park DeVille Drive, Suite A
Columbia, Missouri 65203

E. Lynn Jenkins, M.A. (A)
Actg Chief, Injury Surveillance Section
National Institute on Occupational Safety and Health
1095 Willowdale Road, MS 180-P
Morgantown, West Virginia 26505

Howard R. Kelman, Ph.D. (J)
Research Director
Institute for Urban Family Health
16 East 16th Street
New York, New York 10003

Woodie Kessel, M.D., M.P.H. (I)
Director, Division of Systems, Education, and Science
Maternal and Child Health Bureau
5600 Fishers Lane, Room 18A-55
Rockville, Maryland 20857

Jill M. Killian, B.S. (T)
Data Analyst, Health Services Evaluation
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Selma C. Kunitz, Ph.D. (X)
President
Kunitz and Associates, Inc.
6001 Montrose Road, Suite 920
Rockville, Maryland 20852

John D. Langley, Ph.D. (E)
Director, Preventive/Social Medicine
University of Otago Medical School
P.O. Box 913
Dunedin, New Zealand

Roz Diane Lasker, M.D. (First Plenary)
Director, Division of Public Health
The New York Academy of Medicine
1216 Fifth Avenue
New York, New York 10029-5293

Thomas A. LaVeist, Ph.D. (L)
Assistant Professor
Health Policy and Management
Johns Hopkins University School of Hygiene and Public Health
624 North Broadway, 4th Floor
Baltimore, Maryland 21205

Richard C. Lee, M.S. (P)
Research Analyst
Bureau of Primary Health Care
Health Resources and Services Administration
4350 East West Highway
Bethesda, Maryland 20814

Jack K. Leiss, Ph.D. (I)
Head of Survey Operations
North Carolina State Center for Health and Environmental Statistics
P.O. Box 29538
Raleigh, North Carolina 27626-0538

Joann M. Lindenmayer, D.V.M., M.P.H. (N)
Epidemiologist, Division of Preventive Health Services
Rhode Island Department of Health
3 Capitol Hill, Room 103
Providence, Rhode Island 02908-5097

Suzanne P. Lindsay, M.S.W., M.P.H. (V)
Research Project Coordinator
New Parent Support Program
Children's Hospital
3020 Children's Way, Mail Code 5033
San Diego, California 92131

Shai A. Linn, M.D., Dr. P.H. (E)
Director of Epidemiology
Faculty of Medicine
Rambam Hospital
7/B Rimonim Street
Technion, Haifa
K. Tivon 36000, Israel

David Lohrisch, Ph.D., C.D.P. (D)
Information Systems Consultant
Office of the State Health Officer
Mississippi State Department of Health
P.O. Box 1700
Jackson, Mississippi 39205

Robert A. Lowe, M.D., M.P.H. (G)
Assistant Professor, Center for Clinical Epidemiology and Biostatistics
University of Pennsylvania
240L Nursing Education Building
420 Service Drive
Philadelphia, Pennsylvania 19104-6095

Patricia A. MacCubbin, M.S. (U)
Program Research Specialist IV
Office of Public Health
New York State Department of Health
678 Corning Tower
Albany, New York 12237-0601

Susan MacLean, R.N., Ph.D. (G)
Director of Research Services
Emergency Nurses Association
216 Higgins Road
Park Ridge, Illinois 60068-5736

Gertraud Maskarinec, M.D., M.P.H. (H)
Assistant Researcher
Cancer Research Center of Hawaii
University of Hawaii
1236 Lauhala Street, Room 507
Honolulu, Hawaii 96813

James T. Massey, Ph.D.** (D)
Chief, Survey Design Staff
Office of Research and Methodology

Ian McDowell, Ph.D. (J)
Chairman, Department of Epidemiology
and Community Medicine
University of Ottawa
451 Smyth Road
Ottawa, Ontario K1H 8M5, Canada

Sara McLafferty, Ph.D. (F)
Associate Professor, Department of
Geology and Geography
Hunter College
695 Park Avenue
New York, New York 10021

Lora Means, B.S. (C)
Senior Strategic Policy Analyst
Corporate Utilization Analysis
Blue Cross and Blue Shield of
the Rochester Area
150 East Main Street
Rochester, New York 14647

Janet B. Mitchell, Ph.D. (P)
President
Center for Health Economics Research
300 Fifth Avenue, 6th Floor
Waltham, Massachusetts 02154

Mary E. Murphy, R.N. (D)
Measurement Coordinator, Harwick 8
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Victoria Vespe Ozonoff, Ph.D. (A)
Co-Director, Injury Prevention
and Control Program
Massachusetts Dept. of Public Health
150 Tremont Street, 5th Floor
Boston, Massachusetts 02111

Rena J. Pasick, Dr.P.H. (W)
Associate Director, Prevention Sciences
Northern California Cancer Center
32960 Alvarodo-Niles Road, Suite 600
P.O. Box 5033
Union City, California 94587

Karen L. Power, M.P.H. (B)
Director, Office of Research and
Health Statistics
Boston Department of Health/Hospitals
1010 Massachusetts Avenue
Boston, Massachusetts 02118

Diana M. Rademacher, B.S. (H)
Data Analyst, Harwick 7
Mayo Clinic, Mayo Foundation
200 1st Street, SW
Rochester, Minnesota 55905

Thomas C. Ricketts, Ph.D. (L)
Director, Cecil G. Sheps Center for
Health Services Research
725 Airport Road, CB 7590
Chapel Hill, North Carolina 27599-7590

Christopher Ringwalt, Dr.P.H. (M)
Program Director
Research Triangle Institute
P.O. Box 12194
Research Triangle Park,
North Carolina 27709-2194

Cleone Rooney, M.D. (E)
Medical Statistics Division
Office of Population Censuses
and Statistics
10 Kingsway
London WC2B 6JP, England

Louis Rowitz, Ph.D. (N)
Professor and Deputy Director
Center for Public Health Practice
School of Public Health
University of Illinois
2121 West Taylor Street
Chicago, Illinois 60612-7260

Gerard Rushton, Ph.D. (F)
Professor, Department of Geography
The University of Iowa
316 Jessup Hall
Iowa City, Iowa 52242

Allen L. Schirm, Ph.D. (B)
Senior Researcher
Mathematica Policy Research, Inc.
600 Maryland Avenue, SW, Suite 550
Washington, D.C. 20024-2512

David C. Schutt, M.D. (I)
Director of Quality Management
Department of Defense
The Pentagon, Room 3D372
Washington, D.C. 20301-1200

Harvey A. Schwartz, Ph.D. (W)
Mathematical Statistician, Office of
Science and Data Development
Agency for Health Care Policy/Research
2101 East Jefferson, Suite 602
Rockville, Maryland 20852-4908

James Edward Shmerling, M.S., M.B.A. (O)
Chief Operating Officer
LeBonheur Children's Medical Center
One Children's Plaza
Memphis, Tennessee 38103

Gordon S. Smith, M.B., M.P.H. (E)
Associate Professor
Injury Prevention Center
Johns Hopkins School of Hygiene
and Public Health
624 North Broadway, Hampton House
Baltimore, Maryland 21205

Matthew W. Stagner, Ph.D. (M)
Senior Policy Analyst
Children and Youth Policy
Office of the Assistant Secretary for Planning and Evaluation, DHHS
200 Independence Avenue, SW, Room 450G
Washington, D.C. 20201

Jan A.J. Stolwijk, Ph.D. (First Plenary)
Susan D. Bliss Professor of Epidemiology and Public Health
Yale University School of Medicine
60 College Street, P.O. Box 8034
New Haven, Connecticut 06520-8034

Dorothy McCraw Syblik, M.S., M.B.A. (D)
Statistician
SANUS Healthplan, Inc.
2425 West Loop South, #1000
Houston, Texas 77027

Emmanuel A. Taylor, Dr.P.H. (W)
Senior Epidemiologist, Office of the Associate Director for Minority Health
CDC
1600 Clifton Road, NE, MS A-50
Atlanta, Georgia 30333

Robert Throop, B.A. (R)
Data Manager, HIV Ontario Observational Database
Sunnybrook Health Science Center
2075 Bayview Avenue, Room G315
North York, Ontario M4N 3M5 Canada

Dennis Utter (O)
Chief, Sample Design and Quality Control
State Data Branch
National Highway Traffic Safety Admin.
400 7th Street, SW
Washington, D.C. 20590

Lois M. Verbrugge, Ph.D., M.P.H. (V)
Distinguished Research Scientist
Institute of Gerontology
University of Michigan
300 North Ingalls
Ann Arbor, Michigan 48109-2007

Deborah N. Wallace, Ph.D. (K)
Project Leader
Consumers Union
101 Truman Avenue
New York, New York 10703-1057

Roderick Wallace, Ph.D. (S)
Technical Director, Public Interest Scientific Consulting Service, Inc.
549 West 123 Street, Suite 16F
New York, New York 10027

Joyce C. West, M.P.P. (C)
Research Manager, Office of Research
American Psychiatric Association
1400 K Street, NW
Washington, D.C. 20005

Lauren Westbrook, Ph.D. (M)
Assistant Professor of Pediatrics
Albert Einstein College of Medicine
1300 Morris Park Avenue, Room 7S-20
Bronx, New York 10461

Carla D. Williams, M.A., B.A. (C)
Research Assistant
Center for Mental Healthcare Research
University of Arkansas for Medical Sciences
4301 West Markham Street, Slot 554
Little Rock, Arkansas 72205

Robert M. Williams, M.D., Dr.P.H. (G)
Adjunct Professor
School of Public Health
University of Michigan
6546 Lower Shore Drive
P.O. Box 498
Harbor Springs, Michigan 49740

Deena R. Zimmerman, M.D., M.P.H. (G)
Assistant Professor of Clincial Pediatrics, Department of Pediatrics
Robert Wood Johnson Medical School
1 Robert Wood Johnson Place
New Brunswick, New Jersey 08904

**National Center for Health Statistics
6525 Belcrest Road
Hyattsville, Maryland 20782

EXHIBITORS

Agency for Health Care Policy and Research
Agency for Toxic Substances and Disease Registry
Bureau of Justice Statistics/Office of National Drug Control
Centers for Disease Control and Prevention
The Federal Committee on Statistical Methodology
Indian Health Service
National Center for Health Statistics

DEPARTMENT OF
HEALTH & HUMAN SERVICES

Public Health Service
Centers for Disease Control and Prevention
National Center for Health Statistics
6525 Belcrest Road, Room 1100
Hyattsville, Maryland 20782

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